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MENSTRUAL HEALTHCARE: AN ANALYSIS AND CALL TO ACTION

Addressing provider-related barriers to meeting menstruation associated healthcare needs

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In deze masterproef is een literatuuronderzoek uitgevoerd met als doel om barrières die de zorg voor menstruatie-gerelateerde klachten belemmeren aan te pakken. Hiervoor werd een combinatie van kwalitatieve onderzoeksmethoden gebruikt, waaronder snowball-sampling, inhoudsanalyse en keyword searches. Zowel historische als psychologische perspectieven werden ingezet om de verzamelde data te analyseren. De hoofdvraag richtte zich op het identificeren van de vaardigheden en informatie die medische- en zorgprofessionals nodig hebben om adequaat te reageren op de zorgbehoeften van mensen met menstruatie-gerelateerde klachten. Om een antwoord op deze vraag te formuleren, werd de analyse gestructureerd rond drie deelvragen:

1. Wat zijn onvervulde gezondheidszorg behoeften van mensen met menstruatie-gerelateerde klachten? Het onderzoek onthulde dat patiënten vaak te maken krijgen met onverschilligheid, een gebrek aan erkenning en respect, vertraging in het ontvangen van een diagnose en ontoereikende ondersteuning.
2. Wat zijn de barrières voor het vervullen van deze behoeften vanuit medische- en zorgprofessionals? Veelvoorkomende barrières zijn *medical gaslighting*, het normaliseren van klachten, een gebrek aan kennis over het diagnosticeren en behandelen van aandoeningen gerelateerd aan menstruatie, en een negatieve houding tegenover patiënten met deze problematiek.
3. Wat zijn onderliggende en onderhoudende factoren van deze barrières? Diverse disfunctionele ideologieën en valse overtuigingen die bijdragen aan het in stand houden van deze barrières werden geïdentificeerd en uitgewerkt binnen hun historische context. Bovendien werden de beperkingen van het heersende biomedische zorgmodel kritisch geëvalueerd.

De bevindingen en inzichten uit deze analyse werden gebruikt om aanbevelingen te formuleren voor educatieve programma's voor medische- en zorgprofessionals. Deze aanbevelingen bevatten onder andere het belichten en ontkrachten van valse overtuigingen, het integreren van de historische context onderliggend aan deze overtuigingen, en het incorporeren van interdisciplinaire kennis. In het bijzonder kennis over de impact van psychosociale factoren als menstruele schaamte en pijncatastrofering. Aanbevelingen voor praktische educatie richten zich op het includeren van trainingen voor diagnostische vaardigheden, evenals trainingen in gespreksvaardigheden die specifiek gericht zijn op het bespreken van gestigmatiseerde en potentieel gevoelige onderwerpen.

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In this thesis, a literature review was conducted with the aim of addressing provider-related barriers to meeting the needs of individuals seeking healthcare for menstruation associated symptoms. A combination of qualitative research methods was utilized, including snowball sampling, content analysis and keyword searches. Both historical and psychological perspectives were employed to analyze the data. The main research question focusses on identifying the skills and information required for healthcare professionals to adequately address these neglected healthcare needs. To formulate an answer to this question, the analysis was structured around three sub-questions:

1. What are unmet menstrual healthcare needs? It was revealed that patients frequently experience dismissal, a lack of respect, diagnostic delay and inadequate support.
2. What are provider-related barriers to these unmet needs? Common barriers included medical gaslighting, the normalizing of symptoms, a lack of knowledge on how to diagnose and treat menstruation associated conditions and negative attitudes towards these patients.
3. What are factors underlying and maintaining these barriers? Several dysfunctional ideologies and false beliefs that contribute to sustaining these barriers were identified and discussed within their historical context. Additionally, the limitations of the prevailing biomedical model of care were critically evaluated.

The findings of this analysis were utilized to formulate recommendations for topics and trainings to include in educational programs for healthcare and medical professionals. Recommendations include addressing false beliefs, integrating historical context and incorporating interdisciplinary knowledge. In particular knowledge about the impact of psychosocial factors such as menstrual shame and pain catastrophizing. Practical education should encompass the training of diagnostic skills and training of conversational skills specifically targeted at discussing stigmatized and potentially sensitive topics.

Woord vooraf

Allereerst wil ik graag mijn waardering uitdrukken richting mijn begeleiders, die me de vrijheid en het vertrouwen hebben gegeven om mijn eigen onderwerp te kiezen voor deze masterproef. Ik ben tevens dankbaar voor de aanmoedigingen om te schrijven over wat mij intrigeert. Deze steun heeft mijn enthousiasme voor dit werk versterkt.

In deze thesis richt ik mij op een onderwerp dat beladen is met diepgaande problemen en onrechtvaardigheden. Ondanks de zwaarte van de thema's die besproken worden is mijn benadering geworteld in de zoektocht naar oplossingen. Het doel is om niet alleen bewustzijn te creëren of schuldigen aan te wijzen, maar om constructieve discussies te stimuleren over mogelijke wegen naar verbetering.

Gezien menstruatie, seksualiteit, geslacht en gender altijd geladen onderwerpen zijn geweest, is het belangrijk om aandacht te besteden aan de impact van woorden. In dit paper is er specifieke zorg besteed aan het respectvol hanteren van terminologie. Soms, zoals bij gebruik van het woord "*women*", is de interpretatie afhankelijk van de context. In historische context duidt het woord "*women*" bijvoorbeeld op iedereen die destijds zo werd gezien en behandeld. Het is echter van belang om te erkennen dat niet alle vrouwen menstrueren en dat niet iedereen die menstrueert een vrouw is.

Met deze gedachten in het achterhoofd wens ik u veel leesplezier toe.

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1 Abbreviations

CPP	Chronic Pelvic Pain
HMB	Heavy Menstrual Bleeding
MCAS/D	Menstrual Cycle Associated Symptoms and/or Distress
DSM 5	Diagnostic and Statistical Manual of Mental Disorders
GnRH	Gonadotropin-Releasing Hormone
IAMPD	International Association for Premenstrual Disorders
ICD-11	International Statistical Classification of Diseases and Related Health Problems
PMD	Premenstrual Disorder
PMDD	Premenstrual Dysphoric Disorder
PME	Premenstrual Exacerbation
PMS	Premenstrual Syndrome
TCIM	Traditional, Complementary and Integrated medicine
TCM	Traditional Chinese Medicine

2 Introduction

Despite the essential role of the menstrual cycle in overall health as a reflection of the functioning of the reproductive, endocrine and immune systems, menstrual health is often overlooked in science and medicine (Critchley et al., 2020). In scientific medical discourse and clinical practice, there is a concerning lack of consensus regarding the cut-off point for considering distressing menstrual changes as a valid medical concern that necessitates attention and intervention.

Many people experiencing distressing changes in the luteal or early menstrual (i.e. perimenstrual) phase of their menstrual cycle feel ashamed and uncertain about what is considered normal or healthy due to the normalization of menstrual pain and the stigma surrounding menstruation. This taboo causes millions of people to suffer in silence for long periods of time (Grace & MacBride, 2007; Scott, Hintz & Harris, 2022). People that do seek help frequently encounter healthcare professionals that do not know how to help or don’t take their concerns seriously. Many individuals with heavy bleeding or extreme menstrual pain report difficulty finding relevant information and navigating the healthcare system (Li et al, 2020). A systematic review of 104 qualitative studies on the experiences of over 3800 menstruating people across 16 high-income countries found that most people with distressing perimenstrual symptoms feel unsupported by healthcare professionals because their concerns are often dismissed (Barrington, Robinson, Wilson & Hennegan, 2021). When concerns were acknowledged, the patient was often told they just had a low pain threshold or that the symptoms were a normal aspect of being a woman. They were either given advice on taking painkillers or were told there was nothing that could be done (Barrington et al., 2021). Many people report worries about taking medications, are not satisfied with these answers or prefer not to rely on pharmacological solutions for the rest of their reproductive years. As a result of these worries and the lack of available healthcare, many turn to self-help strategies or alternative modalities of medicine (Barrington et al., 2021; Chan, Rubtsova & Clark, 2023; Arentz, Smith, Redmond, Abbott & Armour, 2021). Often self-prescribed without any professional guidance (Barrington et al., 2021; Fisher, Sibbritt, Hickman & Adams, 2016).

Positive interactions with healthcare providers where patients felt heard and were assisted in finding effective solutions and pain management strategies were reported less frequently (Barrington et al., 2021). Being supported by healthcare professionals made patients feel relieved, it reduced their mental burden and it improved their relationships and participation in a variety of activities. These positive healthcare interactions were generally preceded by many negative experiences. These findings show that there is a need for both general and specialized healthcare providers to be more knowledgeable on the topic of menstrual health, and more aware of the needs of people suffering from problems related to their menstrual cycle. This study therefore aims to address the unmet needs of people experiencing distress associated with the menstrual cycle. It will propose recommendations for topics and trainings to include in educational programs for healthcare and medical professionals, in order to provide them with the right knowledge and tools for supporting these currently unmet needs. These recommendations will be based on a historical and psychological analysis of factors influencing contemporary provider-related barriers to adequate menstrual healthcare.

3 Method

This thesis will be a narrative literature review answering the question ‘What skills and information do healthcare professionals need in order to provide adequate support to people suffering from *Menstrual Cycle Associated Symptoms and/or Distress* (MCAS/D)?’. This question will be answered with the help of 3 sub-questions:

1. What are the unmet needs of people experiencing MCAS/D?
2. What are provider-related barriers to meeting these needs?
3. What are the factors underlying and maintaining the continued lack of medical support for MCAS/D?

The aim of this review is to address the provider-related barriers for meeting the needs of people experiencing Menstrual Cycle Associated Symptoms and/or Distress (MCAS/D). Because an appropriate term that encompasses all symptoms and distress associated with the menstrual cycle does not yet exist in scientific literature, the term MCAS/D was utilized for the purpose of this thesis. MCAS/D includes perimenstrual symptoms, chronic pelvic pain and distress due to these symptoms. Perimenstrual symptoms refers to the regular appearance or worsening of distressing physiological, affective or cognitive changes during the luteal or early menstrual phase of the menstrual cycle. *Chronic Pelvic Pain* (CPP) refers to cyclic as well as non-cyclic chronic pelvic/lower abdominal pain in individuals with female reproductive biology. Pelvic/lower abdominal pain may be associated with the perimenstrual phase (dysmenorrhea), but even when it is not, people often tend to associate the phenomenon with the menstrual cycle if it occurs in someone with female biology. This can lead to similar risks of stigmatization, normalization and diagnostic delay as experienced by people with perimenstrual symptoms (Grace & MacBride, 2007; Scott, Hintz & Harris, 2022).

3.1 Procedure

Literature on the unmet needs and provider-related barriers of specific (peri) menstrual symptoms (e.g. mood swings, abnormal uterine bleeding, dysmenorrhea) and conditions associated with these symptoms (e.g. perimenstrual disorders, endometriosis, fibroids, chronic pelvic pain) were analyzed to gain insight into the current state of menstrual healthcare in western medicine.

Databases used for the literature search included PubMed, LIMO, and google scholar. The search terms that were used for answering the first two research questions include “unmet needs”, “provider related barriers” and “barriers to care” in combination with various definitions for menstruation-associated symptoms and conditions like: “dysmenorrhea”, “Premenstrual disorders”, “Premenstrual syndrome”, “Premenstrual dysphoric disorder”, “PMS/PMDD”, “Chronic pelvic pain”, “abnormal uterine bleeding”, “heavy menstrual bleeding”, “endometriosis” and “PCOS”. During the literature review, it was observed that terms for the same or similar conditions often varied across fields of research. New terms discovered during the review were also incorporated into the search. For instance, in the case of chronic pelvic pain in women, some urological/gynecological studies defined it as “chronic pelvic pain syndrome”, and some studies with a more integrative or feminist approach tended to use the term “cyclic perimenstrual pain or distress”.

Given the broad and interdisciplinary nature of the aim of this thesis, snowball sampling, content analysis and keyword searches were the primary methods for acquiring new information and stimulating further inquiries to address the research questions. To ensure a patient-centered perspective, specific attention was dedicated to the voices of people experiencing MCAS/D. This involved including viewpoints from organizations associated with patient-platforms in the analysis. The organizations that were included for this purpose are EndoAwareness BE/NL and the International Association for Premenstrual Disorders (IAPMD).

3.2 Data analysis

For a comprehensive exploration of the factors contributing to healthcare barriers, both historical and psychological perspectives were adopted in the analysis. The historical approach served as a foundation for contextualizing the issue of provider-related barriers through examining the sociocultural, religious and medical influences that have shaped contemporary diagnostic and treatment processes. Cultural historian Elinor Cleghorn’s (PhD) book “*Unwell women, A journey through medicine and myth in a man-made world*” (2021) has been a valuable source, providing an historical account of the medical treatment of women with distressing symptoms and conditions associated with the female reproductive system. Additionally, a psychological approach was employed to gain insight into how societal attitudes and perceptions may impact the provision of healthcare services for individuals seeking solutions for MCAS/D. This involved examining literature on gendered norms and beliefs, menstrual stigma and emotions associated with the female reproductive system.

Part I Exploration of the problem

4 Introducing the problem

In both medical and non-medical contexts, physiological (e.g. bloating, dysmenorrhea), emotional (e.g. mood swings, irritability) and cognitive (e.g. anxiety, difficulty concentrating) changes frequently associated with the luteal and early menstrual phase of the female reproductive cycle are often referred to as PMS or *premenstrual syndrome*. The term premenstrual syndrome was first coined in 1953 by Katharina Dalton, a British endocrinologist who opened the first PMS clinic in London. She claimed that about 50% of women became “ill” with PMS every month, and frequently told reporters that these women “owed it to their family to seek treatments for their bad moods” (Taylor, 2006; Chrisler & Caplan, 2002). She defined the construct as “any symptoms or complaints that regularly appear just before or during the early days of menstruation but are absent during other times of the cycle”, and treated her patients with progesterone hormone suppositories and injections (Figert, 2005;Tayor, 2006). By the 1970’s PMS had started to receive more attention from biomedical and behavioral scientists, and by the 1980’s it was an established cultural phenomenon due to its successful usage as a plea for diminished responsibility in two sensationalized murder trials that received world-wide publicity. The attorney of one of the accused claimed that the “hidden animal” inside his client would emerge if her progesterone injections were not administered to control her PMS. Journalists then popularized the concept of PMS and the notion that normal women could be turned into dangerous criminals due to premenstrual hormone fluctuations (Chrisler &Caplan 2002).

In contemporary non-medical settings, PMS is generally presumed to be a fairly common biological phenomenon. The term is often used as a way of expressing premenstrual discomfort or to downplay, trivialize or make fun of the experiences of women expressing negative emotion. While some people may feel validated by the public legitimization of PMS symptoms, the perception of PMS as something that controls women and makes them irrational once a month has many harmful political, relational and health-related consequences. Including, paradoxically, the normalization of perimenstrual discomfort and an increased risk of mistrust in the accounts of people experiencing perimenstrual symptoms.

In scientific discourse the construct of premenstrual syndrome has always been highly controversial and subject to criticism. These criticisms range from issues surrounding the lack of agreement on how to define, diagnose and research the condition, to concerns regarding its existence as an actual medical entity and the impact of its common usage on the medicalization of the female body and the perpetuation of gender stereotypes (Chrisler & Caplan, 2002; Ussher, 2004). Scientific articles have attributed up to 150 different symptoms to PMS and estimates of the prevalence range from 2 to 100% depending on the research method and diagnostic criteria used (Chrisler & Caplan, 2002).

Despite its poorly defined diagnostic criteria being widely recognized, the term is still used in modern-day medical literature. Many contemporary articles view PMS as falling on a spectrum of premenstrual disorders (PMD's) ranging from PMS, with a prevalence often estimated somewhere between 10 to 60%, to *Premenstrual Dysphoric Disorder* with an estimated prevalence of 1,2 to 6,4% (Gao et al., 2022; Goswami et al., 2023; Takeda, 2023). Premenstrual dysphoric disorder (PMDD) is often considered a more legitimate form of PMS due to its recognition and agreed upon diagnostic criteria in the DSM 5 (Diagnostic and Statistical Manual of Mental Disorders) and ICD-11 (International Statistical Classification of Diseases and Related Health Problems), where a minimum of 5 symptoms must be reached to qualify for a diagnosis. The conceptualization of PMDD and its inclusion in these manuals has however, similar to PMS, been subject to criticism (Offman & Kleinplatz, 2004; Chrisler & Caplan, 2002; Hartlage, Breaux & Yonkers, 2014).

In this paper the term premenstrual syndrome or PMS will not be utilized to refer to perimenstrual symptoms or distress. This decision was made due to the construct being poorly defined and rooted in misogynistic speculation. In existing literature there are various terms for conditions or symptom-spectra that are related to or associated with the menstrual cycle, like chronic pelvic pain, dysmenorrhea or cyclic perimenstrual pain or distress. However, there is no appropriate term that encompasses all symptoms currently associated with the menstrual cycle as well as the distress due to menstrual cycle related changes or symptoms. In previous ages the term *hysteria*, might have been used to refer to uterus-associated symptoms, but over time this word has been appropriated to describe an exaggerated display of emotion and to define various psychological issues that have little to do with either the uterus or the menstrual cycle. For these reasons the term *perimenstrual symptoms* will be used when discussing distressing perimenstrual changes and symptoms, and the term *Chronic Pelvic Pain* (CPP) will be used to refer to pelvic pain symptoms that are associated with but may or may not be related to the menstrual cycle. When discussing the whole range of symptoms and distress associated with menstruation by healthcare professionals or individuals that may seek healthcare for their concerns, *Menstrual Cycle Associated Symptoms and/or Distress* (MCAS/D) will be utilized.

To shed light on various aspects of difficulties experienced in seeking and receiving care for MCAS/D, the following chapters will explore unmet needs and provider related barriers within the context of a physiologically identifiable condition, premenstrual disorders (PMD’s), chronic pelvic pain (CPP), and abnormal uterine bleeding. It is important to recognize that all of these different aspects of MCAS/D are interconnected and often co-exist in reality. However, existing research has mainly focused on each of these aspects separately. A comprehensive understanding of the overall barriers to achieving adequate menstrual healthcare is still lacking. The first part of this thesis will therefore aim to contribute to filling that gap and provide a comprehensive examination of the literature on provider-related challenges faced by individuals with MCAS/D seeking healthcare. The second part of this thesis will focus on exploring solutions for resolving these barriers and meeting the healthcare needs of people experiencing MCAS/D. These solutions will primarily focus on essential updates that need to be made to the curriculum for individuals seeking careers in medical and healthcare sectors. Additionally, implementing supplementary training programs for those already working in these fields will be discussed.

The first context in which unmet needs and barriers to care will be explored is when the symptoms are due to a physiologically diagnosable condition. Exploring MCAS/D within this context will illustrate how MCAS/D symptoms are treated when explanations for what is causing MCAS/D exist and are generally accepted within the traditional biomedical framework. There are several physiological conditions that can result in MCAS/D. A few examples are polycystic ovarian syndrome (PCOS), fibroids, adenomyosis and endometriosis. People suffering from these conditions generally face similar struggles getting their healthcare needs met. For the purpose of demonstrating these unmet needs, endometriosis was chosen to represent this group of conditions. The reason for this choice is that endometriosis can present itself as a variety of MCAS/D symptoms, has a high prevalence, and is relatively well-researched compared to other conditions.

Secondly, provider-related barriers to meeting the needs of people presenting with symptoms that may be due to premenstrual disorders (PMD’s) will be explored. The process for identifying these conditions is primarily based on diagnosing severe psychological and affective perimenstrual symptoms. Examining barriers to care within this context sheds light on the challenges associated with treating conditions that intersect between two fields of medical specialization that both carry cultural taboos: gynecologic and mental healthcare. Lastly, barriers to care for two specific MCAS/D symptoms will be discussed: abnormal menstrual bleeding and pelvic pain associated with menstruation. Examining barriers to care for these aspects of MCAS/D sheds light on perceived challenges within western medicine to diagnose and treat MCAS/D symptoms, stemming from the exclusion of subjective experiences in the diagnostic process and problems distinguishing between normal menstrual variations and potential pathology.

5 Endometriosis

One of the most prevalent conditions resulting in MCAS/D is endometriosis, a disease where tissue similar to the endometrial lining grows outside of the uterus and can cause adhesions, scarring and extremely painful inflammatory reactions. Endometriosis is the leading cause of subfertility in individuals with female biology, and is estimated to have a prevalence of 18% in Europe. Pelvic or abdominal pain due to endometrioses is estimated to affect 6 to 10% of the population. (As-Sanie et al., 2019; Moradi et al., 2021). People suffering from this condition can experience a multitude of symptoms ranging from severe pain in the pelvic region, fatigue, heavy bleeding and depression to gastrointestinal and urinary issues, collapsed lungs and pain in the legs, hips or lower back. On average patients have to wait 7 to 12 years for a diagnoses after the onset of symptoms, which has been shown to significantly decrease the quality of life and increase the risk of infertility (As-Sanie et al., 2019; Marinho et al., 2018; Debolt, 2023). A Belgian study on the societal impact of endometriosis-associated symptoms estimated that the annual cost per patient is €9872 (Klein et al., 2014). A large portion of these costs are due to productivity loss, while hospitalizations, surgeries, infertility treatments, pain and anxiety also have a significant impact. Klein et al. (2014) argue that earlier diagnosis may reduce total costs significantly trough a decrease in productivity loss, healthcare consumption and quality of life impairment.

Despite the high impact and prevalence of this condition, many healthcare professionals lack the knowledge necessary to diagnose and provide treatment for their patients. A French study found that 50% of the 100 surveyed general practitioners could not name 3 out of the 5 main symptoms (dyspareunia, dysmenorrhea, chronic pelvic pain and infertility) of endometriosis (Quibel, Puscasiu, Marpeau & Roman, 2012). Another study found that 50% of gynecologists falsely believed that an early diagnosis of endometrioses cannot prevent worsening of the disease because an effective treatment does not exist (cited in As-Sanie et al., 2019). In reality there is a variety of treatment options available. The endometriosis tissue can be surgically removed and for the management of pain symptoms many guidelines recommend hormone treatments (Kalaitzopoulos et al., 2021). Other symptom-management treatments include nonsteroidal anti-inflammatory drugs, presacral neurectomy, GnRH agonists, aromatase inhibitors, acupuncture, electrotherapy, and dietary products and vitamins. However, several of these treatments for managing symptoms are not suitable for long-term use, and guidelines frequently have conflicting opinions on what is the best line of treatment (Kalaitzopoulos et al., 2021)

5.1 Barriers to care

In one study addressing the unmet needs of endometriosis patients, the reasons for diagnostic delay are extensively discussed (As-Sanie et al., 2019). It is argued that the societal normalization of women’s pain and the taboo and stigma surrounding menstruation and female sexuality play a pivotal role in this delay. Patients may be hesitant to discuss MCAS/D symptoms or dyspareunia with their healthcare providers, and the professionals do not recognize the relevance, believe the severity or feel uncomfortable initiating or facilitating discussion about these kinds of symptoms (As-Sanie et al., 2019). One small US-based study interviewing 6 women about their pre-diagnostic experiences with medical providers found that medical providers were the second most common source of normalization of symptoms, only second to the patients themselves. The participants reported feeling like they were not listened to and all had experience with medical specialists, gynecologists and endocrinologists being dismissive towards their symptoms (Debolt, 2023). As-Sanie et al. (2019) similarly found that dismissal and downplaying of symptoms by professionals and refusal to refer to specialists were important factors leading to diagnostic delay. Patients on average visit 7 general practitioners before being referred, sometimes to the wrong specialists. Other concrete reasons for the diagnostic delay that were identified are: outdated guidelines for clinicians that have often not been updated for 5 to 10 years, the relatively high risks and costs associated with laparoscopy as main method for diagnosing endometriosis, a lack of clinician’s understanding about the spectrum of symptoms and the etiology of endometriosis, the process of ruling out other diseases, frequent misdiagnoses (3/4 of patients receive a misdiagnoses, often Irritable Bowel Syndrome or Inflammatory Bowel Disorder) and a perceived lack of time for sufficient consultation.

In september 2020 De Schamphelaere and Vandaele from EndoAwareness BE/NL, an organization collecting testimonials of people suffering from endometriosis, wrote an open letter addressed to the Belgian minister of public health, and healthcare professionals in Belgium and The Netherlands. They address several common shortcomings and misconceptions in endometriosis care and formulated a list of 7 essential concerns and opportunities for improvement (retrieved from https://endoawarenessbenl.wordpress.com/basistekst-brief/):

1) “A need for more attention to the complex condition that is endometriosis in medical schools.” They argue that endometriosis should not just be seen as a gynecological condition due to its possible impact on organ and nerve function outside of the pelvic region.

2) “Faster diagnosis and improvement of doctors' knowledge and expertise so that symptoms are quickly recognized.” They emphasize the importance of a change of attitude for many healthcare professionals because of the frequency of condescending remarks and prolonged suffering due to dismissal and rejection experienced by patients.

3) “Doctors and information brochures of medical or other institutions systematically provide incorrect and/or incomplete information.” The lack of sufficient knowledge translation between scientific research and clinical practice is emphasized, evidenced by the fact that patients who informed themselves by reading scientific literature on the condition were frequently more knowledgeable than their healthcare providers.

4) “Preoperative treatment methods such as GnRH analogues are systematically used in Belgium and the Netherlands, despite discouragement by the ESHRE guideline and specialized endometrioses surgeons, due to severe side effects and the lack of medical benefits.”

5) “At the moment there is no adequate training as a "pelvic endometriosis surgeon". Surgeons specialized in fertility perform the operation currently, but they don’t necessarily possess the advanced skills necessary for treating complex endometriosis.”

6) “Physicians should promptly refer patients to other and/or higher domestic or foreign expertise.” They emphasize the need for an attitude change where physicians prioritize the health and needs of the patient over their own interests and ego.

7) “Patients should have access to foreign (surgical) endometriosis expertise and receive reimbursement for this. According to European guidelines this should be possible but Belgian health insurance funds often refuse this.”

5.2 Hormonal contraceptives

In an attachment to the letter they expand on several of these issues and provide a list of examples of common incorrect and unprofessional remarks made by healthcare professionals extracted from the testimonials (e.g. “just get pregnant, that will cure it”, “just wait until you’re in menopause”, “you’re too young to get endometriosis”). Patients frequently receive wrong or incomplete information and advice. In the attachment the importance of correctly informing patients is emphasized, so they can make informed decisions in choosing suitable treatment options for themselves. One example that is mentioned of a commonly occurring scenario of professionals misinforming their patients, is when they automatically prescribe girls and women *hormonal contraceptives* for MCAS/D symptoms that may indicate endometriosis, without the appropriate framing or follow up. This medication can in some cases relieve the pain or decrease the intensity of menstrual bleeding, and thus reduce a distressing symptom. However, contrary to popular belief, contraceptive hormone treatments do not “regulate” the menstrual cycle or prevent the progression of endometriosis (Millochau, Darwish, Huet, Dietrich & Roman, 2016). Medicating with hormonal contraceptives creates an artificial state in the female body, similar to when it is in the early stages of pregnancy. The main purpose of this is to decrease monthly hormone fluctuations and in the majority of cases prevent ovulation from occurring, leading to suppression of the menstrual cycle. This approach can be effective in alleviating perimenstrual symptoms for some individuals, and oral contraceptives have been shown to reduce and delay postoperative recurrence of endometrioma (Seracchioli et al., 2010). However, it is essential to recognize that the only currently known evidence-based effective treatment of the underlying disease is surgical removal of the endometriosis tissue (Kalaitzopoulos et al., 2021). Promoting the masking of symptoms and framing it as a preventative measure or even a treatment for the disease can have harmful consequences. The disease can spread and grow into a more complex, dangerous and difficult to treat condition, while going unnoticed by the patient. Sometimes for decades, until the medication is stopped.

This tendency to automatically prescribe hormonal contraceptives as treatment for endometriosis or other conditions resulting in MCAS/D symptoms without providing the correct information and follow-up is frequently mentioned in articles pointing out scientific and clinical barriers to adequate menstrual care (As-Sanie et al., 2019; Barrington et al., 2021; Chan, Rubtsova & Clark, 2023). From the perspective of healthcare professionals, reluctance to taking hormonal contraceptives as treatment for MCAS/D is often perceived as problematic and a result of misconceptions. In one study interviewing 15 midwives working at Swedish youth clinics about supporting girls with menstrual pain, participants framed hormonal contraception as “A natural choice and an effective method for pain relief”. Resistance to this supposed solution by mothers or the girls themselves was perceived as originating from fear due to cultural perceptions about sexuality and menstruation, a lack of knowledge, and misconceptions about the risks of hormonal contraception (Eldestrand, Nieminen & Grundström, 2022). Informing these patients about the “true” risks associated with hormonal contraceptives was seen as the solution to this problem.

However, mistrust in hormonal contraception recommendations by medical professionals is not ungrounded. Hormonal contraception is often falsely promoted as a way of “regulating” hormones or the menstrual cycle, and the risks associated with this medication are often minimized or not even mentioned. A study analyzing gynecology and medical textbooks found that the risk assessment method used for hormonal contraception in medical textbooks is biased, resulting in medical professionals systematically downplaying their side effects (Bertotti, Mann & Miner, 2021). For assessing the risks of different contraceptive options, they are ranked by typical use failure rates in a tiered model. Bertotti et al. (2021) argue that by organizing and assessing contraceptive methods in this way, prevention of pregnancy is prioritized over other concerns like adverse side effects and bodily autonomy. It was discovered that medical textbooks justify the logic of this emphasis on contraceptive failure rate trough a misleading discourse that conflates two characteristics often used to assess pharmaceuticals: efficacy (ability to achieve intended effect) and safety (lack of unintended adverse effects). Discourse on efficacy magnifies lifestyle risks (individual behavior, decisions and priorities) and embodied risks (characteristics of bodies) while downplaying medical risks (consequences of medical procedures or treatments), leading to a biased process of risk assessment. The first bias Bertotti et al. (2021) identified is that ovulation, menstruation and pregnancy are defined as inherently dangerous (bodily risk). The second bias implies that people with female reproductive biology who don’t actively self-manage their contraception are a danger to society (lifestyle risk). These two underlying assumptions justify the playing down of hormonal contraceptive medical risks, and the framing of women who decline or are hesitant about considering these options as misguided and irrational. In other words, emphasis on the intended effect of hormonal contraceptives, medication primarily promoted as a method for controlling the female reproductive system and preventing pregnancy, leads to biased risk assessment where biologically female bodies are seen as a risk to themselves and to society. Hormonal contraceptive medication is therefore perceived as automatically worth the risk of side effects because it solves social and health problems that are perceived to be caused by female bodies and women’s behavior (Bertotti, Mann & Miner, 2021). This automatic assumption inhibits women’s right to bodily autonomy by denying them the right of making informed decisions about their treatment options.

6 Premenstrual disorders

6.1 Confusion and controversy

Premenstrual disorders are a controversial topic. As with many other conditions affecting mental health, there is significant stigma and skepticism regarding their existence, resulting in patients presenting with these diagnoses or related symptoms not being respected or taken seriously (Thornicroft, Rose & Kassam, 2007; Osborn, Wittkowski, Brooks, Briggs & O'Brien, 2020) The association with menstruation enhances both the stigma and the skepticism. Many medical and healthcare professionals are either unaware of PMD's or do not recognize their legitimacy as real disorders (Chan, Rubtsova & Clark, 2023; Osborn et al., 2020). The historical, political and social dimensions of the classification of these conditions will be discussed in later chapters. The current chapter will primarily address the unmet needs and provider-related barriers experienced by people seeking care for symptoms that match contemporary diagnostic criteria for PMD's.

In a population-based study conducted in Switzerland, 91% of the 3913 women sampled reported at least one premenstrual symptom, 10% fulfilled the criteria for their definition of PMS, and 3,1% qualified for the DSM IV diagnostic criteria for PMDD (Tschudin, Bertea & Zemp, 2010). The most commonly reported symptoms were physiological changes like breast tenderness, headaches, joint/muscle pain, cramping, bloating and weight gain (74%), mild to severe anger or irritability (57%), and tearfulness and mood swings (57%). It was reported that for 15% of the participants the symptoms were so severe they required medical intervention. It was however not clarified whether this judgment was based on the opinion of the participants, their medical providers or the researchers (Tscudin et al., 2010). The emphasis for PMD research and receiving a diagnosis for PMS or PMDD mainly lies on the quantity and severity of psychological and affective symptoms, despite the fact that dysmenorrhea and other physiological symptoms are more common and have been repeatedly identified as most disruptive to quality of life (Przybylo & Fahs, 2018; Tschudin et al., 2010; Ju, Jones & Mishra, 2014; Rae, 2020).

The International Association for Premenstrual Disorders (IAPMD), a patient-led organization committed to centering the lived experiences of patients in PMD research and clinical practice, classifies Premenstrual Dysphoric Disorder (PMDD) and *Premenstrual Exacerbation* (PME) as PMD's (retrieved from https://iapmd.org). The viewpoints of the IAPMD are evidence-based and primarily guided by the work of Tory Eisenlohr-Moul (PhD). Similar to some of the previously mentioned recently published papers on PMD's found on LIMO and PubMed (Gao et al., 2022; Goswami et al., 2023; Takeda, 2023), PMDD is viewed as more severe and less common than PMS. PMS is described as a collection of physical and emotional symptoms that are more easily managed than PMDD symptoms and do not require prescription medication. The organization does not provide information on how these symptoms supposedly can be managed more easily without medication, or how to determine whether or not medication is necessary. The importance of distinguishing PMS from PMDD and using correct terminology is emphasized because of the differences in etiology, diagnoses and treatments, and to help spread awareness about PMDD. The organization provides valuable information about PME and PMDD for patients, providers, and researchers. However, when it comes to dealing with distressing perimenstrual changes that are not severe enough to be classified as PMDD, or symptoms that do not stem from a recognized underlying disorder, information is not yet available on the website.

In a study by Eisenlohr-Moul (2019) written as primer and research agenda on PMD’s for psychologists, the DSM-5 classification is utilized to conceptualize PMDD. In the DSM-5 PMDD is categorized as a mood disorder and characterized by a clear confinement of symptoms in the luteal phase, meaning that there is full remission after the onset of menstrual bleeding. The fact that PMDD is primarily defined by its time course instead of its content makes it unique among mental disorders (Eisenlohr-Moul, 2019). For a diagnosis at least one of the core affective symptoms must be present (mood swings; rejection sensitivity; anger/irritability; interpersonal conflict; depressed mood; hopelessness; feelings of worthlessness/guilt/anxiety) and 5 or more of the additional symptoms (decreased interest; difficulty in concentration; lethargy or lack of energy; increased cravings or appetite; hypersomnia or insomnia; feeling overwhelmed or out of control; physical symptoms)(Eisenlohr-Moul, 2019).

Eisenlohr-Moul notes that there are many pervasive misconceptions in circulation about the etiology of PMDD, for example that it is caused by hormonal imbalance, abnormal hormone levels or an abnormal hormone metabolism. Research has shown that PMDD patients and controls cannot be differentiated by measuring hormone levels, patterns or metabolism across the menstrual cycle (as cited by Eisenlohr-Moul, 2019). Findings by Schmidt et al. (2017) suggest that PMDD patients are affected by an abnormal sensitivity to normal post-ovulatory hormone fluctuations. Recent neurobiological findings suggest that PMDD patients might have abnormal expressions of genes that process hormones and an altered sensitivity to allopregnalone in the brain. However, the exact biological mechanisms behind this sensitivity have not yet been uncovered (Dubey et al., 2017; Timby et al., 2017; Bixo et al., 2018; Eisenlohr-Moul, 2019). The few studies examining psychological mechanisms underlying PMDD found that there is an influence of historical trauma and stress on symptom severity and that PMDD patients show higher trait levels of avoidant and impulsive behaviors and brooding rumination(Eisenlohr-Moul, 2019). PMDD patients also experience a premenstrual increase in self-focused attention which partially mediates symptom severity (Craner, Sigmon & Young, 2016).

6.2 Premenstrual Exacerbation

In the primer, Premenstrual exacerbation of an underlying disorder (PME) is described as “the worsening of chronic symptoms of an existing psychiatric disorder before or during menstruation” (Eisenlohr-Moul, 2019). This worsening of symptoms during the luteal and menstrual phases has been reported to occur in many conditions like migraines, epilepsy, diabetes and asthma, and in mental disorders like anxiety disorders, psychotic disorders and eating disorders (Pinkerton, Guico-Pabia & Taylor, 2010). These findings suggest that PME does not only occur in psychiatric conditions. However, so far the prevalence of PME has only been estimated for depressive disorders. One epidemiologic study found that of the 900 interviewed menstruating participants, 58 had a depressive disorder or depressive symptoms. Around 60% of those participants reported significant premenstrual exacerbation of at least one symptom (Hartlage, Brandenburg & Kravits, 2004). However, despite the existence of evidence for a high prevalence of this phenomenon for several conditions, premenstrual exacerbation is not yet widely acknowledged or assessed in clinical practice. Eisenlohr-Moul argues for adding ‘with premenstrual exacerbation’ as a diagnostic specifier for PME in the next DSM to indicate the possible need for specific treatment options for this complicating factor. Because several clinical trials have found that people with PME of depression do not respond well to hormone suppression, it is suggested that PME has a different biological etiology than PMDD, and that unlike PMDD patients, people with PME of depression have a sensitivity to withdrawal or depletion of hormones (Eisenlohr-Moul, 2019). More research on PME of various different conditions is necessary to better understand the phenomenon, use the information to detect specific disorders and help determine whether different treatments can help prevent this phenomenon. PME is still only in the beginning phase of attracting scientific attention, despite the fact that its predecessor *Premenstrual Magnification* was already suggested in 1985 by psychiatrist Michelle Harrison (Harrison, 1985). Due to the phenomenon not yet being widely recognized, no literature on the unmet healthcare needs of people experiencing PME exists. To inspire increased attention for PME in the future, it is critical that students aspiring to work in the fields of medicine and psychology learn about its existence, as well as the fact that we still lack important information about this issue.

6.3 Barriers to care

When it comes to PMDD, more research on unmet needs and provider related barriers has been coming out in the last couple years. One study interviewing 15 women from the UK about their experiences with receiving and living with a PMDD diagnosis, found that it took an average of 20 years for people to get diagnosed (Osborn et al., 2020). Their findings suggest that when PMDD is left undiagnosed and untreated, patients develop substantial comorbidities as coping strategies. Including substance misuse problems, eating disorders and suicidal ideation and behavior. Participants reported that they were frequently misdiagnosed and that they felt pressure to comply with treatments despite their concerns about the prescribed drugs being ineffective and sometimes even harmful. When they did bring up concerns about being misdiagnosed, many were met with unwillingness form their healthcare providers to consider alternative causes for their mental health problems and MCAS/D symptoms (Osborn et al., 2020). The researchers also found that participants were frequently accused of exaggerating or faking the severity of their symptoms and that they were often told that their mood symptoms were just a normal part of being female. This mistreatment resulted in the participants feeling belittled, ridiculed, ashamed, helpless and hopeless. Osborn et al. (2020) observed that receiving recognition for their suffering in the form of a diagnosis of PMDD had a significant positive impact on the lives of PMDD patients. Due to the previous lack of identifiable causes or triggers for their intense feelings, many participants felt shame, self-hatred and self-blame because of the belief they were crazy or had a fundamentally flawed personality. The explanation of the existence of a physiological cause for their symptoms transformed their sense of identity. Participants reported being able to better make sense of past experiences and understand how things were beyond their control after receiving an official diagnosis. Getting the right pharmaceutical treatment (GnRH agonists) was similarly described as life-changing. The fact that symptoms disappeared after starting this treatment was perceived as ultimate proof that their problems were related to their menstrual cycle.

Participants described feeling an overwhelming sense of relief when they were finally taken seriously, and a sense of safety when they had found a provider who understood and supported them. However, for most participants the difficulties did not disappear after receiving a diagnosis. Many of them felt immense sadness and grief in relation to the life they could have had, had they been diagnosed earlier. Additionally, they were met with the challenge of having to reinvent who they were. Participants also reported still having to fight for recognition after their diagnoses, and being left with ongoing mistrust in medical professionals (Osborn et al., 2020). Another study interviewing 32 American PMDD patients similarly found that even after receiving an official diagnosis, patients still had to convince each new healthcare provider that PMDD was real and that they had it (Chan et al., 2023). This is particularly problematic given the fact that it often is not possible for patients to receive treatment from the same provider they received a diagnosis from in many healthcare systems. Findings by Chan et al. (2023) were similar to the previously mentioned study by Osborn et al. (2020). Participants were frequently misdiagnosed, dismissed, disrespected, and not listened to with regards to previous failed treatments, resulting in medical trauma and mistrust in healthcare professionals. Patients were not taken seriously unless their symptoms had an obvious direct physiological impact on their fertility, for example in patients with comorbid diagnosed PCOS or endometriosis. Nineteen of the thirty-two participants self-diagnosed before eventually receiving a diagnosis from a medical professional, and 3 participants got diagnosed by a parent or a partner first. Some participants saw up to 10 healthcare providers before they received an official diagnosis.

Chan et al. (2023) identified several provider-related barriers leading to insufficient care from the interviews. Medical professionals did not have the tools and knowledge necessary for diagnosing and treating PMDD and there is insufficient coordination among different healthcare providers and specialists. A common phenomenon is healthcare providers “quitting” on PMDD patients, stating there is no longer anything they can do to provide help. The researchers observed that the power dynamic between the healthcare providers and patients can function as a provider-related barrier (Chan et al., 2023). This dynamic results in doctors failing to acknowledge and utilize patient-provided information. A common occurrence of this issue is when patients present information about the symptoms that they have tracked, but healthcare providers refuse to look at this information. This behavior is unprofessional and poses a significant problem, as self-advocacy and recognizing the cyclical nature of symptom severity have been identified as crucial factors in the process of receiving a diagnosis and managing PMDD. With regards to receiving the preferred treatment method, many participants reported feeling uneasy about the lack of caution with which providers prescribed first line pharmaceutical treatments (hormonal contraception/antidepressants) for PMDD without any follow-up appointments. PMDD patients are frequently prescribed around five different medications, and the first line of treatments often only works partially. Second line or alternative treatment options like chemical or surgical menopause (GnRH agonists/ bilateral oophorectomy) were prescribed with much more caution, despite the fact that they work better at relieving all symptoms and don’t have the effect of increasing the risk of suicidal ideation and behavior, which hormonal contraceptives or antidepressants can have in people with PMDD (Chan et al., 2023).

6.4 Medical gaslighting

Chan et al. (2023) described the dismissal and normalizing of symptoms experienced by participants as *medical gaslighting*. Gaslighting refers to a person psychologically manipulating someone else into questioning their own reality. This behavior caused participants to doubt and downplay their own symptoms and impacted their ability to advocate for themselves, resulting in further diagnostic delay (Chan et al., 2023). One participant described this phenomenon as medical professionals being reluctant to admitting their own lack of knowledge, and instead telling the patient that they are mistaken because the professional does not understand what is going on. The term ‘medical gaslighting’ first appeared in medical literature in 2020 in the context of a patient suffering from long-covid not being taken seriously, and has since then frequently been used on social media in the context of healthcare providers downplaying or dismissing MCAS/D symptoms (Durbhakula & Fortin, 2023).

Sebring (2021) argues that certain underlying ideologies within the field of western medicine make it susceptible to the practice of medical gaslighting. One of these ideologies is *positivism*. Positivism gained prominence during the age of enlightenment in the 17th and 18th centuries. It refers to the idea that the world can only be truly understood trough applying the scientific method, and that it exists independent of our subjective experience. This ideology fosters the false notion that all aspects of medicine are measurable, objective and unbiased. This perspective can justify medical gaslighting by ignoring patients lived experiences and thus erasing their reality. Positivism in medicine does not only contribute to the relegation of certain conditions, like PMS or PMDD, to “fake” or “all in the head” when a definite biological explanation has not yet been uncovered or widely accepted, but it can also be used to justify attributing social circumstances to biological causes. For example in the case of the historical phenomenon of hysteria, where women who did not conform to feminine ideals of the time were pathologized (Sebring, 2021).

Another ideology that perpetuates medical gaslighting is *Cartesian dualism*, which refers to the idea of the body and mind being distinct entities (Sebring, 2021). Within this framework, the mind is associated with rationality, intellect and reason, while the body is linked to emotion. The ideal promoted by Cartesian dualism is dominance of the “strong mind” over the body’s perceived “excessive” emotions. Throughout history these ideas have had far-reaching implications and have contributed to the persistence of androcentrism, still present in the field of medicine today (Sebring, 2021; Samulowitz, Gremyr, Eriksson & Hensing, 2018; Hølge-Hazelton & Malterud, 2009). Cisgendered, heterosexual, white, upper-class males were typically associated with the mind and considered the ideal and healthy norm, while everyone else was perceived as inferior and subject to the unruly body (Sebring, 2021). One example of how dualism relates to medical gaslighting is by how it assigns inherent value to the words of people with bodies or identities that are associated with “the mind” (e.g. white men, academics, scientists, medical professionals) and devalues people with certain other possibly intersecting identities, features or conditions (e.g. people of color, women, overweight individuals, individuals with mental health conditions) that are (symbolically) associated with “the body” or its emotions. The complicated relation between these ideologies and their interaction with MCAS/D will be explored further in subsequent chapters.

6.5 Who cares?

One aspect of modern western medicine that clearly demonstrates the persistence of this dualism is the separation into biomedical disciplines focusing on one specific bodily system, and psychological and psychiatric disciplines focusing on the mind. In this system modalities focusing on the mind tend to be devalued due to their association with supposed “weakness”. In a study examining provider competency ratings of 2512 participants seeking healthcare for PMDD symptoms, the uncertainty about which provider to approach due to PMDD being situated on the intersection of gynecologic and mental healthcare was identified as an additional provider-related barrier (Hantsloo et al., 2022). As mentioned earlier, the IAPMD uses the DSM 5 diagnostic system, which classifies PMDD as a mood disorder, suggesting the need for a psychologist or psychiatrist. However, the ICD-11 classifies PMDD as a disease of the genitourinary system cross listed under depressive disorders, suggesting the need for a gynecologist, psychiatrist or endocrinologist (Hantsloo et al., 2022).

In this study on provider-competency, four different kinds of providers (general practitioners, gynecologists, psychiatrists and therapists) were rated in three key areas of competence: awareness and knowledge of PMDD diagnosis and effective treatments, concrete indicators of expertise (the use of daily symptom rating tools) and interpersonal factors (compassion, basic validation and willingness to learn about PMDD) (Hantsloo et al., 2022). There are significant differences in how different specialists scored on these three competence factors from the perspective of patients. General practitioners were rated the lowest on interpersonal factors and also scored badly on the other two factors. One study found that only 11,5% of 87 surveyed physicians reported routinely using tools for 60-day daily symptom monitoring (Craner, Sigmon & McGillicuddy, 2014). These findings are concerning since general practitioners are often the first healthcare provider PMDD patients come into contact with (Hantsloo et al., 2022). This might be due to the fact that in many healthcare systems, patients need a referral from a general practitioner to be able to see a gynecologist, therapist or psychiatrist, or get insurance back for the consultation (Hantsloo et al., 2022). Therapists were rated highest on interpersonal factors, but lowest on basic awareness of PMDD and effective treatments. Psychiatrists also underperformed on this factor. These findings might be due to poor education. Very little to no attention is paid to reproductive psychiatry in psychology or psychiatry curriculums (Hantsloo et al., 2022).

7 Women's pain

7.1 The challenge of not knowing

There is a gap in medical literature on unmet healthcare needs of people experiencing perimenstrual pain symptoms, despite the fact that this is the most common perimenstrual change women experience. A search for unmet needs or provider related barriers in healthcare specifically for dysmenorrhea reveals limited meaningful results. Two studies mentioned frequent dismissal and difficulty in finding relevant information for pain relief and management, and in navigating the menstrual healthcare system (Li et al., 2020; Mann et al., 2013). In a recent study interviewing girls with primary dysmenorrhea, referring to perimenstrual pain since menarche, the authors observed that their needs for social and emotional support were often unmet (Varshney & Kimport, 2023). Varshney and Kimport argue that this should be addressed by healthcare providers.

Literature on unmet needs and provider-related barriers in healthcare for women with Chronic Pelvic Pain (CPP) is more comprehensive. Chronic Pelvic Pain refers to persistent, cyclical and non-cyclical, intermittent or continues lower abdominal pain, lasting for at least six months (Grace & MacBride-Stewart, 2007). CPP can include various pain symptoms like dysmenorrhea, dyschezia and dysuria (pain with defecation or urination), and dyspareunia (pain that comes with penetrative sex). A study interviewing 40 women with CPP asking them to reflect on "how come" they have pelvic pain found that for most women, it is difficult to differentiate pelvic pain that is related to menstruation from pain that is not (Grace & MacBride-Stewart, 2007). Pelvic pain without a cyclical pattern was frequently understood to be originating from the same causes as pain that comes with menstrual periods (e.g. assuming that all women's pelvic pain is "probably hormonal"), leading to its normalization trough similar means. Scott, Hintz & Harris (2022) found that normalization of pelvic pain is connected to communication about menstrual pain early in life.

Grace and MacBride-Stewart observed that uncertainty was an integral aspect of the participants accounts, even when a potential cause for the pain was suggested by their healthcare provider. Participants responded to the uncertainty of not knowing in two distinct ways. One response to uncertainty about pelvic pain was a lack of concern (e.g. "I don't know why there is pain but it doesn't matter because it's normal"). For another group the uncertainty caused them to worry about whether there possibly could be something wrong medically. The researchers identified a significant sense that being able to visualize where the pain comes from would help to bind it in some way (Grace & MacBride-Stewart, 2007). Women's imaginations about the source of their pain were frequently based on their understanding of biomedical discourse. This means that it was either explained as being related to imbalanced hormones, or trough metaphors of internal organic injuries, especially when the pain started after childbirth. The authors argue that the absence of physiological pathology combined with imagined organic injury or dysfunction as source for the pain creates “a gendered normalization of speculated dysfunction and injury in relation to women’s pelvic pain” (Grace & MacBride-Stewart, 2007). This implies that not only the pelvic pain itself, but also anxieties surrounding pelvic pain are normalized in people with female reproductive biology.

According to Grace and MacBride-Stewart, referral to hormones in the accounts of the participants seems to metaphorically invoke archaic medical speculation about enigmatic and unruly processes in the female body that are deemed “normal” but at the same time capable of wreaking havoc and causing disturbance, including pain. This phenomenon highlights the fact that women’s pelvic pain, and the ideas people have about it, challenges the conventional dichotomous biomedical distinction between “normal” and “pathological”. The prevalence of dismissal, denial and normalization of menstrual pain by healthcare providers could in part be due to the challenge it presents to the worldview of individuals whose perspective on health and normality is deeply influenced by the positivistic, dualistic and androcentric framework inherent to the biomedical model. Healthcare professionals who learned to view the world through this limited lens may experience the various causes and meanings menstruation-associated pain can have as a potential threat to their beliefs, causing them to either (subconsciously) assume inherent fault in the female body and mind, or try to discredit, invalidate or deny the phenomenon altogether.

7.2 Gender bias

In a study reviewing chronic pain literature with the aim of understanding gender bias in pain perception and pain treatment in clinical settings, it was observed that chronic pain in general tends to be perceived as feminine, and as a challenge for the field of medicine (Samulowitz, Gremyr, Eriksson & Hensing, 2018). Speculation about explanations for sex-differences in pain perception or reporting frequently included mentions of menstruation and childbirth. Some studies suggested that women are more used to internal pain due to these phenomena and others claimed that pain without any external cause is just a natural characteristic of the female body (Samulowitz et al., 2018). These findings suggest that ideas about menstrual pain or the pain of childbirth are sometimes generalized to the whole body and mind of the menstruating individual.

Findings by Samulowitz and colleagues confirmed the presence of a paradox in medicine where women are at a greater risk for many clinical pain conditions and are socialized to talk about and show their pain more compared to men. However, when they do, it is taken less seriously and frequently discounted as nonexistent or psychological. The researchers explain this paradox trough the presence of *hegemonic masculinity* and *andronormativity* in medicine. The concept of hegemonic masculinity is explained as “a pattern of masculine attributes, behaviors, and practices which are constructed as the prevailing and idealized norm and against which both men and women are evaluated” and andronormativity describes the phenomenon of “masculine and male values being regarded as normal in medicine to such an extent that femininity and female values are invisible and need to be highlighted in order to be recognized” (cited from Samulowitz et al., 2018).

Women with pain symptoms are generally described in scientific pain literature as more sensitive and more willing to report their pain compared to men (Samulowitz et al., 2018). Men were not described in comparison to women, and were generally thought of as stoic and in the habit of denying or tolerating pain. Women with chronic pain were frequently perceived as emotional, hysterical, complaining, malingering or not wanting to get better, and experienced by healthcare providers as time consuming and frustrating. A bias based on gendered values and norms instead of biological differences has been observed in scientific literature on pain, in clinical practice, and in prescribed pharmaceuticals (Hoffman & Tarzian, 2001; Samulowitz et al., 2018). Women were more likely to receive a prescription for anti-anxiety or anti-psychotic drugs for their pain, while men received medication that was meant to relieve pain for their pain.

7.3 Barriers to care

In the context of MCAS/D symptoms, the tendency to psychologize women’s pain is a significant provider-related barrier to care. This tendency is evident in scientific literature addressing MCAS/D and in clinical practice. Despite the higher impact and prevalence of perimenstrual pain symptoms, scientific research predominantly concentrates on treating psychological and affective aspects of MCAS/D with pharmaceuticals (Gao et al., 2022). In clinical encounters this inclination to psychologize women’s pain concerns creates a troubling vicious cycle. Pain coupled with distress is primarily attributed to psychological factors. When a patient communicates distress, a behavior predominantly ingrained in women trough socialization, this frequently results in a greater degree of psychologization and a tendency to undermine the seriousness of the pain. Samulowitz and colleagues explain this trough the presence of hegemonic masculinity. Psychological problems are feminine-coded and thus down-valued compared to somatic conditions, leading women to feel their pain is dismissed when it is psychologized. Paradoxically, feeling mistrusted or being excessively subjected to psychologization by healthcare providers intensifies distress, subsequently increasing the risk of further psychologization. Psychosocial factors have been shown to increase premenstrual symptoms as well as premenstrual distress. Rosvall & Ekholm (2016) found that 32% of variance in premenstrual distress can be predicted by psychosocial factors like raising children, adopting avoidant coping mechanisms, perfectionism and engaging in self-silencing. However, simply attributing pain accompanied by distress to distress is counterproductive and lacks professionalism. Healthcare providers need to be better educated on how and when to address psychosocial factors in relation to MCAS/D.

In line with Grace and MacBride-Stewart's finding that many women with CPP worry about their pelvic pain, studies on *pain-catastrophizing* in chronic pain literature reveal significantly higher levels of catastrophizing in individuals with CPP compared to the general population suffering from chronic pain (Joseph & Mills, 2019). Joseph and Mills (2019) identified a lack of targeted intervention focused on catastrophizing to improve CPP treatment outcomes as a provider-related barrier in gynecological healthcare. Pain-catastrophizing involves magnifying the perceived threat of pain, struggling to control pain-related thoughts before, during and after the pain, and experiencing feelings of helplessness when in pain. In the short term pain catastrophizing can have benefits because it promotes problem solving, reduces negative emotions associated with pain-related anxiety and elicits social support. However, in the long term it drives maladaptive affective and behavioral responses. Pain catastrophizing is a strong predictor for worse pain-related outcomes and more pain-related disability. Considering the impact of catastrophizing on pain and the prevalence of this phenomenon in CPP patients, it is crucial to address this factor in the treatment process (Joseph & Mills, 2019).

Joseph and Mills (2019) argue that the traditional biomedical approach to pain management lacks solid evidence and does not take into account existing knowledge on the development and persistence of chronic pain conditions. The biomedical perspective assumes that underlying organic pathology is primarily responsible for ongoing pain, and that the degree of this pathology determines the severity of pain. Research on chronic pain conditions has repeatedly demonstrated that this assumption is false and that there is no direct link between tissue pathology, and presence, duration or severity of pain (Joseph & Mills, 2019). In the context of pelvic pain, research has revealed that biomedical factors do not predict pain severity, impact on quality of life, or response to treatment (Weijenborg, ter Kuile, Gopie & Spinhoven, 2010). A purely biomedical treatment approach might not only be ineffective in relieving CPP symptoms for many individuals, but can have the potential to further exacerbate catastrophic worry, cause iatrogenic harm and intensify the pain experience (Joseph & Mills, 2019). In their study, Joseph and Mills found that 75% of the 100 participants with CPP who were referred to a gynecological outpatient service in Colorado report moderate to severe levels of pain-catastrophizing worry. This percentage is significantly higher compared to other chronic pain conditions, but also higher compared to other studies measuring catastrophic worry in CPP patients, for example in CPP patients being treated in an interdisciplinary setting (Allaire et al., 2018).

Given the fact that CPP is estimated to account for roughly 10% of outpatient gynecologic visits (Witzeman & Kopfman, 2014), it is essential to implement changes in the gynecological curricula and healthcare systems to accommodate the switch from a biomedical to a multidisciplinary socio-psycho-biomedical approach. In a study assessing the need for changes in the curriculum for obstetrics-gynecology residents, it was found that most residents believed that they were not adequately prepared for addressing the needs of CPP patients (Witzeman & Kopfman, 2014). The residents frequently reported feeling overwhelmed by these patients and had negative attitudes towards working with CPP patients. However, they universally reported a desire to improve their knowledge on CPP. Factors that were identified as potentially influencing these negative attitudes towards CPP patients and CPP complaints were a perceived lack of time, a lack of confidence, the influence of negative attitudes of their mentors, the commonality of CPP, empathy, and limited knowledge on pain medications (Witzeman & Kopfman, 2014).

7.4 Neglected modalities

Another essential body of knowledge that needs to be integrated into healthcare systems and medical literature on MCAS/D is Traditional, Complementary and Integrative Medicine (TCIM). The World Health Organization uses TCIM as an umbrella term for traditional medicine, complementary medicine and herbal medicine (retrieved from who.int). Over half of women with chronic pelvic pain report using at least one TCIM treatment approach in the past year (Chao et al., 2015). The self-perceived efficacy of these treatments varies across TCIM modalities but is generally high, ranging from 33% to 97% (Fisher et al., 2016). Traditional Chinese Medicine represents a promising field within TCIM for managing and treating CPP. Early scientific evidence for the effectiveness of acupuncture and Chinese herbal medicine in reducing pelvic pain is encouraging (Lund &Lundeberg, 2016; Yang et al., 2017). However, because people have a tendency to view these treatment modalities as natural and therefore low risk, many people use them without guidance or supervision of a professional TCIM practitioner and don’t communicate these treatments to allopathic healthcare providers, which can have harmful consequences (Fisher et al., 2016).

A study exploring CPP knowledge amongst TCM practitioners and barriers to integration of TCM in the wider healthcare system surveyed 122 TCM practitioners based in New Zealand (Arentz, Smith, Redmond, Abbott & Armour, 2021). One hundred and eleven practitioners reported regularly treating pelvic pain and dysmenorrhea, but treatment of dyspareunia and dyschezia was less common. During a TCM consultation the severity of the pain was frequently assessed by asking questions, using pain scales, taking notes of their history, and asking about the amount of pain medication drugs that is used. More than half of practitioners additionally reported assessing their patients using the traditional TCM method of examining the pulse and the tongue. Progress of treatments was frequently assessed using similar methods. It should be noted that in the allopathic medical literature on MCAS/D treatments reviewed for this current paper, questioning the amount of analgesic pharmaceuticals to assess pain severity was not mentioned anywhere. The focus was predominantly on the scarce use of evidence-based pain scale tools and informing healthcare providers on which (additional) pharmaceuticals to prescribe.

About half of the surveyed TCM practitioners reported integration within the wider healthcare system. They regularly referred patients for biomedical testing or to other TCIM and allopathic healthcare providers. However, many TCM practitioners reported a lack of referral pathways in healthcare settings as a barrier to sufficient care for CPP patients (Arentz et al., 2021). The lack of interprofessional referrals within healthcare systems has been identified as a leading cause of patient harm (Nguyen, Smith, Hunter & Harnett, 2019). Key factors contributing to the absence of interprofessional communication are dominance of the biomedical model and a lack of clarity regarding each other's roles (Nguyen et al., 2019). Other barriers to supporting CPP patients that were reported by TCM practitioners were the financial expense, the inconvenience of frequent treatments, and adverse effects of treatments (Arentz et al., 2021). Most mentions of adverse effects consisted of increased intensity of pain or additional pain in other parts of the cycle, and were mainly associated with acupuncture. Limited evidence of effectiveness of TCIM treatments and limited evidence-based clinical practice were also reported as provider-related barriers, partly due to insufficient research (Arentz et al., 2021). Prejudice against TCIM evident in medical literature could play a role in the scarcity of evidence for the effectiveness of treatments, and in the lack of interprofessional communication. An example of prejudice against TCIM in medical literature is when women seeking acupuncture treatment are described as “desperate women”, while women using pharmaceuticals with similar levels of evidence-based effectiveness are not described in this way (Arentz et al., 2021). The authors argue that this kind of negative bias towards TCIM treatments may influence attitudes of TCM practitioners towards evidence-based practice, leading some practitioners to believe it is useless or unnecessary (Arentz et al., 2021).

Arentz et al. (2021) argue that limited interprofessional communication between allopathic and TCIM healthcare practitioners may be partly due to perceived incompatibility of the dominant biomedical framework where the body is seen as a collection of mechanistic interactions, and more holistic frameworks where there is an emphasis on the body, mind and emotions being interconnected and inseparable. For individuals raised with the traditional western ideas of how the body and mind function, concepts needed for understanding the TCM diagnostic and treatment process like Yin, Yang or Qi may sound strange and be challenging to comprehend. However, neither the traditional biomedical model nor the more evidence-based and integrative psycho-socio-biomedical models have been entirely successful in finding reliable and effective ways for meeting the needs of people suffering from MCAS/D. Creating more familiarity with alternative diagnostic and treatment methods in individuals working in western healthcare disciplines might foster collaboration and inspire new ways of looking at the complicated situation of MCAS/D.

One example of a TCIM phenomenon that warrants attention within medical education to create a better understanding of MCAS/D, is the way TCM practitioners perceive a normal menstrual cycle. In the study by Arentz and colleagues (2021), practitioners reported that at least 25% of patients with CPP present with an abnormal menstrual cycle. An abnormal cycle was defined by an imbalance between yin and yang, insufficient or stagnant Qi, and temperature irregularities (Arentz et al., 2021). This contrasts significantly with the western interpretation of an abnormal menstrual cycle, which encompasses four domains related to menstrual blood: frequency of bleeding episodes, predictability or regularity of these episodes, their duration, and the volume of bleeding (Chritchley et al., 2020). Another example that might be beneficial to fostering a better understanding of MCAS/D and easier interprofessional collaboration is to provide all medical professionals with a basic understanding of commonly understood TCM mechanisms thought to underly CPP symptoms. These include “hyper-inflammation”, “blood stasis”, “qi or cold stagnation”, “yang deficiency” and “damp phlegm” (Arentz et al., 2021).

8 Abnormal Uterine bleeding

8.1 Dirty blood

For centuries, most of the dominant religions have depicted menstrual blood and the menstruating body as spiritually and physiologically ‘impure’ or ‘unclean’, which has resulted in menstruation being a taboo subject in many cultures (Tan, Haththotuwa & Fraser, 2017). Menstruating women are still to varying degrees expected to isolate themselves from society or refrain from certain activities like cooking food, having sex or entering sacred places during their menstrual period, due to fear of them causing pollution and contagion (Bhartiya, 2013). In more secularized cultures religion does not play an explicit role in prohibiting menstruating people from living their lives freely anymore, but the tendency to emphasize hygiene and secrecy generally remains (Moloney, 2010; Barrington et al., 2022; Owen et al., 2022). Women are encouraged to hide their period and all the accompanying symptoms, and when they don’t succeed in doing this, it is generally seen and experienced as dirty and shameful (Barrington et al., 2021; Henry, Jefferies, Ekeroma & Filoche, 2020). This lasting emphasis on hygiene and secrecy has devastating effects on individuals experiencing distressing menstrual symptoms, and prevents them from seeking timely care (Henry et al., 2020; As-Sanie et al., 2019; Barrington et al., 2021).

Over the ages, religious speculation on menstruation and menstrual blood has significantly influenced medical theorizing. Unfortunately, these groundless and outdated views on menstruation still persist in contemporary research objectives, medical literature and clinical practice. By analyzing the way in which the male and female reproductive systems are depicted in medical textbooks, Martin (1991) revealed that the words that are used to describe these structures and processes convey specific values that match gender ideals of the time, and have nothing to do with the reality of how these systems function. The male system is generally described as active and heroic, while the female system is depicted in a more negative light, as predominantly passive and wasteful (Martin, 1991). Martin argues that considering ovulation as the primary purpose of this intricate organ system that happens to possess the ability to grow new humans, leads to the portrayal of the menstrual phase of the cycle as a failure. As a result of adherence to this simplistic, reductionistic and one-dimensional perspective on the purpose of the menstrual cycle, medical textbooks describe menstrual blood with words like “debris”, and the menstrual process itself as “dying”, “losing” or “expelling” (Martin, 1991). By perpetuating this association with waste and death, medical discourse contributes to the misconception that menstruation is an unnecessary and burdensome ailment. This perspective on menstruation fails to recognize the essential role of the menstrual cycle in the endocrine, immune an reproductive systems, and undermines the understanding of menstruation as a vital aspect of female physiology. A study conducted in 2014 observed that medical, as well as middle- and high school biology textbooks still use gendered language to describe the reproductive process, in similar ways as to how Martin revealed this to be the case more than 30 years ago (Campo-Engelstein & Johnson, 2014).

8.2 Barriers to care

As a result of the stigma surrounding menstruation and menstrual blood, research on menstrual blood and its seemingly obvious potential for aiding in diagnosing menstrual problems has been largely neglected until recently (Chritchley et al., 2020). This neglect persists, despite the fact that methods for easily collecting menstrual blood have been available for over 80 years. Early evidence of its potential usage for detecting endometriosis seems promising and highlights the importance of routinely integrating new developments within this field of research in the curriculum for medical education and supplementary training programs for healthcare professionals (Chritchley et al., 2020).

In 2018 the gynecologic health and disease branch of a US-based organization held a two-day meeting with the goal of identifying gaps and opportunities in menstruation-related science (Chritchley et al., 2020). They identified several barriers to adequate healthcare specifically affecting individuals with abnormal and distressing menstrual bleeding patterns. Within the biomedical model, alterations to the pattern or volume of uterine bleeding are defined as the symptom *abnormal uterine bleeding*. It is estimated that 30% of individuals with female reproductive biology experience this symptom (Chritchley et al., 2020). Abnormal uterine bleeding can be an indication for a complex combination of conditions, classified by the acronym PALM (for structural conditions)-COEIN (for non-structural conditions). This classification system accounts for 88% of underlying causes for abnormal uterine bleeding, it encompasses the remaining 12% under “not yet classified” represented by the last letter “N” (Henry et al., 2020). The lack of attention for other symptoms like pain, fatigue and anxiety in clinical settings was identified as a provider-related barrier.

Another problem that has been brought to light is the persistent tendency of clinicians to exclusively rely on objective laboratory measures for diagnosing menstrual problems and evaluating treatment effectiveness. In the context of abnormal uterine bleeding, this entails a specific amount of blood loss that is considered normal. According to the International Federation of Gynecology and Obstetrics (FIGO), losing 40 mL of blood over 5 to 7 days is normal, and losing over 100 mL of blood throughout a cycle is considered as the symptom *heavy menstrual bleeding* (HMB) (Henry et al., 2020). This approach, rooted in the positivist paradigm discussed earlier, overlooks the crucial aspect of subjective experiences in the diagnostic process. A positivistic approach is inadequate for diagnosing and treating heavy menstrual bleeding and many other symptoms associated with menstruation for multiple reasons. From the perspective of women experiencing HMB, the arbitrary threshold defining what is deemed “heavy”, or an objective reduction in mean blood loss, hold little meaning when it comes to the true impact of these symptoms on their lives, or determining the effectiveness of treatments (Chritchley et al., 2020).

Assessing subjective patient experiences of treatment effectiveness would be a more accurate method of measuring treatment effectiveness. In the context of menstrual bleeding this could entail asking questions like: “which methods are utilized to manage the bleeding and how frequently do these methods need to be replaced?”, “how does the bleeding impact your day-to-day life?” and “what would be your preferred outcome of treatment?”. It is worth noting that measuring or inquiring about the amount of menstrual blood loss is a technique that is seldom employed to assess the severity of the situation. This points to a significant disparity between evidence-based recommendations and clinical practice. Instead, individuals with concerns about their blood loss are frequently dismissed or advised to take pain killers, the pill or extra iron, without any further exploration of the problem (Henry et al., 2020). These recommendations can be irresponsible, since painkillers and iron tablets may exacerbate the bleeding. Moreover, HMB can be traumatic and may indicate serious conditions like endometriosis, hyperplasia (pre-cancer) or endometrial cancer, making reluctance to further examine patients with this symptom extremely alarming.

In a study interviewing 15 women about their experiences with seeking care for HMB, several provider-related barriers were identified (Henry et al., 2020). All of the participants reported that their HMB had a significant impact on their quality of life, work, education and relationships. They described facing a multitude of similar provider-related barriers to the ones that were previously mentioned while discussing endometriosis, premenstrual disorders and pelvic pain. For instance, participants reported medical gaslighting, an emphasis on immediate symptom reduction instead of identifying the cause, and what was described as the “doctor trail”. A doctor trail is the phenomenon of spending years trying to find a provider that will listen, support and treat the cause of symptoms. In describing their feelings of being dismissed, participants noted the frequent use of the word “just” by their healthcare providers, as in “just take painkillers/the pill” or “just use a hot water bottle”. They also often felt that they were made responsible for their HMB trough comments like “it’s your weight”, and that the impact of HMB was diminished by comments like “everyone bleeds”. Some participants additionally described a sense of inhibited autonomy with regards to the hormonal contraceptive medications they were prescribed, which aligns with findings by Bertotti and colleagues (2021) about the bias medical professionals have towards prescribing hormonal contraception. Women did not feel they were sufficiently informed about their prescribed medications or alternative treatment options. One participant even reported feeling threatened after a Mirena coil was inserted, despite having specifically mentioned she did not want one (Henry et al., 2020).

8.3 Addressing shame

Numerous women had traumatic experiences with sudden heavy blood loss, where they bled trough their clothes and reported feeling embarrassed (Henry et al., 2020). The interviews revealed that emotions of embarrassment, shame and the fear related to menstruation significantly influence the process of seeking healthcare for heavy menstrual bleeding. These negative emotions contribute to social isolation and a hesitancy to discuss menstrual concerns with healthcare providers (Henry et al., 2020). Extensive research has demonstrated that menstrual shame plays a critical role in diagnostic delay for all MCAS/D conditions (Barrington et al., 2021; Grace & MacBride-Steward, 2007; Scott et al., 2022; Osborn et al., 2020; Henry et al., 2020). Instances of medical gaslighting and minimizing comments further fuel these negative emotions, potentially leading individuals to perceive their symptoms and distress as unworthy of medical attention (Henry et al., 2020). Interestingly, recent research revealed significant positive correlations between menstrual shame, body shame and perimenstrual distress (Ryan, Ussher & Perz, 2020). Additionally, another study discovered that trait body shame is a significant predictor for increased menstruation-related symptoms (Lamont, 2023). These findings suggest that menstrual shame in itself may influence individuals’ experiences of menstruation and perceptions of their menstrual symptoms.

Sharon Moloney (2010) argues that menstrual shame functions as “a core patriarchal organizing principle that inculcates and perpetuates male dominance and female subordination”. Trough instilling fear, self-consciousness and the belief that female physiology is inherently flawed, shame alienates women from their own bodies. It consequently has the potential to destroy bodily confidence and trust in the essential and natural processes of menstruation as well as childbirth (Moloney, 2010). Interviews with women who have experienced giving birth reveal that menstrual shame plays a pivotal role in predisposing women to approach giving birth with a fearful and disempowered attitude, rendering them susceptible to medical interventions (Moloney, 2010). It is essential to acknowledge that while biomedical interventions like pharmaceuticals and surgery can be valuable tools in certain situations where they are needed and/or wanted, they should not be regarded as the primary or sole method for managing natural bodily processes like giving birth or managing the menstrual cycle.

The biomedical perspective on menstruation and birth completely disregards the spiritual component that is associated with these innate processes in many cultures, and portrays these functions as purely physiological, dangerous, and unstable. This approach capitalizes on and exacerbates menstrual shame, perpetuating the belief that female bodies are inherently faulty and therefore dependent on the medical system for their natural bodily functions. However, in doing so it only selectively takes on responsibility, trough overmedicalizing the female body during pregnancy and childbirth. Meanwhile, women that are not currently pregnant, which is the majority of women in the world, are left to bear full accountability for issues with their reproductive system as well as the consequences of fear stemming from internalization of this excessive pathologization. This artificially created sense of dependency and selective responsibility-taking sustain a cycle of disempowerment and anxiety, further perpetuating menstrual shame and MCAS/D. The dominant traditional biomedical model essentially works to pathologize not being pregnant, and overmedicalize being pregnant. In doing so it assumes control over women’s reproductive autonomy, instead of assisting the processes where wanted and needed.

Part II Exploration of solutions

9 Menstrual healthcare

Reviewing the literature on several aspects of MCAS/D reveals that the association with menstruation is a significant factor in preventing patients from receiving support and treatment for their menstrual health concerns. Menstruation-associated pain as well as excessive bleeding, psychological and affective symptoms are normalized and individuals seeking healthcare encounter disbelief, dismissal and a lack of respect. Furthermore, when treatment is offered, they are frequently provided with inadequate information about available treatment options. In certain instances desired treatments are declined while unwanted interventions are imposed. It becomes evident that many healthcare professionals hold false, outdated and dysfunctional beliefs about managing and treating these symptoms and conditions. Analyzing the experiences of individuals presenting with quantifiable physiological symptoms like heavy menstrual bleeding and diagnosable conditions like endometriosis, reveals that the problem is not solely rooted in a lack of scientific knowledge or technological advancement. Rather, a number of common misconceptions persist. Menstruation-related problems are perceived as inherently challenging to address, women are perceived as individually responsible for their own symptoms, and suitable treatments are believed to be scarce or non-existent. These pervasive myths lead to a lack of research on the topic, and a lack of research translation into clinical practice. This deficiency in turn leads to underdiagnosis of these conditions and biased epidemiological research (Hoffman et al., 2021). Hoffman and colleagues point out that research on women’s health issues is deprioritized. The attention it does receive primarily focuses on childbirth and life-threatening conditions like endometrial or ovarian cancer. Non-cancerous gynecologic conditions have historically been marginalized in epidemiologic research because most societies devalue the time, pain and well-being of women.

The lack of attention for MCAS/D in healthcare is a systemic problem that requires a collaborative and multifaceted approach to address. On a broader level, this involves policy and organizational changes, improvements in research infrastructure and increased funding to advance our understanding of different treatment approaches. At an individual level, it is crucial that medical researchers and healthcare providers recognize the significance of this issue within their respective fields, and undergo the education and training necessary to effectively address it. The following chapters will discuss educational subjects and practical trainings logically emerging from the previous analysis of contemporary menstrual healthcare. These educational subjects and trainings will primarily focus on creating a more functional mindset and knowledge foundation, and need to be systematically integrated into curricula and supplementary educational programs for all medical and healthcare professions. The primary goal is to inspire confidence in healthcare providers about interacting with, helping and treating individuals with MCAS/D. The necessity for integration of these educational subjects is amplified for certain healthcare disciplines. The urgency for proactive engagement is particularly pronounced for professions such as general practitioners, gynecologists, endocrinologists, (pelvic floor) physiotherapists, sexologists, psychologists, psychiatrists and medical and healthcare researchers.

10 Awareness of reality

10.1 A dark history

The first step in addressing this issue is to educate (aspiring) professionals about this persistent medical neglect and the underlying reasons behind its longevity. To comprehend the deep rooted nature of these problems present in contemporary western medicine, it is essential to have an understanding of the historical interplay between religion, politics and medicine, and its impact on beliefs about women's bodies and women's health over the past 20 centuries. Key historical topics that need to be addressed for this purpose are the ever-changing conceptualization of hysteria, the enduring consequences of prohibiting women from professionally practicing medicine for over six hundred years, and how the professionalization of the field of gynecology has been shaped by a colonialist mindset. This historical foundation is fundamental for recognizing and understanding contemporary biases in the diagnostic and treatment processes for MCAS/D. Other benefits of providing medical professionals with information about how their respective fields developed is that it might aid in challenging ingrained dysfunctional beliefs and gender norms trough unveiling the changing nature of these beliefs over time. It also reveals the progress we have made, as well as limitations of our current knowledge caused by a dysfunctional allegiance to positivism and Cartesian dualism. This may foster humility and counter the frequently mentioned counterproductive attitude of expertise-driven arrogance, a factor often cited as contributing to the frequent occurrence of medical gaslighting (Chan et al., 2023; testimonials form EndoAwareness BE/NL). Another potential benefit of illuminating these dark aspects of our history is that it may inspire advocacy and motivate professionals to address this historical inequality. The following paragraphs will discuss three pervasive myths that emerged from the exploration of provider-related barriers in the previous chapters within their historical context.

10.2 Just get pregnant

The oldest pseudoscientific idea still influencing contemporary medical and psychological theorizing, is that the solution to all difficulties (sometimes vaguely or falsely) associated with the uterus or menstruation is marriage, intercourse and pregnancy. Influential historical men like Plato and Hippocrates believed that most female illness was due to lonely uteruses without seed wandering through the body. The cure was to weigh them down with a baby (Cleghorn, 2021, p. 23-37). Claudius Galen, often considered the father of modern autonomy, discovered in the first century that the womb in fact does not wander, but the idea remained popular. He observed that symptoms at the time considered to be hysteric (uterus-related), were often correlated with sexual abstinence and frequently occurred in widowed women. Because of this observation he assumed that healthy uteruses produced a semen-like secretion, and that retention or repression of this secretion corrupted the blood or irritated the nerves (Trimble & Reynolds, 2016). This corruption would then result in hysteric symptoms, meaning that the supposed cure was still marriage and intercourse. Historically, any underexplained symptoms (e.g. fainting, epileptic seizures, pain) or undesirable traits or behavior in females (e.g. anxiety, anger, ambition, depression) could be considered hysteric. The exact symptoms varied over time. In later ages the connection with the womb became de-emphasized trough new scientific developments, but the concept of hysteria remained. It should be noted that at this time in history, women were considered the more lustful sex. They were believed to have untamable impulses because of their "biological purpose", and uteruses were thought to hunger for intercourse and pregnancy in ways that were beyond the control of the women they inhabited, thus warranting external control. It was not until after the invention of the printing press in the 16th century, when women started to write and publish stories from their point of view about constantly having to ward off lustful men, that this perspective slowly started to shift (Kaartinen, Linkinen & Heinonen, 2017, p. 116).

Due to the rise of Christianity and the adoption of Christian laws, dissection became illegal and Galen's ideas became the basis for human medicine for over 15 centuries. Medical writings that survived the fall of the roman empire were closely regulated and translated by the church and its male medicine men, who were forbidden from physically examining women (Cleghorn, 2021, p. 29). All of the new writings were based on old ideas extrapolated trough catholic theology. This resulted in influential books like "*secrets of women*", where menstruation was described as the root of all evil and where women were blamed for infertility, miscarriages and birth defects. Books like this were promoted as medical, but primarily gave priests and medicine men instructions on how to punish women for these supposed sins (Cleghorn, 2021, p.40). For most of human history, women would see female healers or midwives about their reproductive health concerns, but when religious men started gaining power these professions became marginalized and outlawed. By the 14th century women were prohibited from professionally practicing medicine. This ban lasted until the late 19th century. Those who continued were tried and sentenced, forcing female healers to revert to secrecy in order to help women in need. The active suppression of women's voices and their exclusion from the discourse facilitated the unchecked proliferation of these false “medical” ideas throughout Europe. Natural disasters like the plague contributed to the escalation of these ideas about female biology as not only harmful but also demonic, supposedly making them susceptible to witchcraft (Cleghorn, 2021 p.42-52).

By the 15th century these dangerous ideas about women were embedded in the minds of men. By the end of that century the pope had included witches as heretics, and the book *Maleus Malificarum* started circulating through Europe. This book claimed ambition and lust made women prone to possession by the devil, and that any female healer attending a compromised childbirth should be suspected of witchcraft (Cleghorn, 2021, p. 48-49).

By the 17th century approximately 45 thousand people were executed for witchcraft, predominantly female healers and other marginalized women over the age of 40 (Cleghorn, 2021, p.51). These supernatural beliefs started to decline and the shift in perspective about men being more lustful compared to women had completely permeated European culture, making way for new medical theories defining what a healthy women is: a passive and obedient married mother. In these new theories the supposed source of hysteric symptoms changed, but the solution remained consistent: marriage, intercourse and pregnancy. The uterus remained a popular target for medical speculation about the issues of women, but emphasis shifted to its supposed close association with the brain and mind, (sexual) emotions and fragile female nerves. Each new discovery, such as the role of the ovary and its mysterious secretions in 1850, or hormones in 1920, led to a resurgence of the old or the formation of new baseless medical theories about how a lack (or excess) of sexual emotion, intercourse, marriage, or conception is the source of all women’s problems.

By the late19th century, this paradigm was reversed. Theories about the influences of psychosocial factors emerged, and Freud popularized this idea by claiming that failure of conception was the result instead of cause of hysteric diseases, arguing that women with these symptoms were sexually underdeveloped due to emotional trauma (Rapetti, Carta & Fadda, 2012). Although his rationale was significant in advancing our understanding of how psychology can also cause physiology, this line of reasoning still implies that the health and maturity of women revolves around pregnancy and motherhood. Freud is often credited with “rescuing” hysteria from misapprehension because he redefined the term. However, instead of retiring the word altogether, he essentially rebranded it as a mental disorder and turned it into a quite literally feminine-coded term for mental illness, strengthening the collective association between femininity and weak-mindedness and popularizing the psychologization of women’s health problems.

In the 20th century several symptoms and conditions of which the etiology was previously thought of as hysteric, like epilepsy and dissociative disorders, started to become better understood, as well as the female reproductive cycle. Because of this, emphasis had now shifted to the functioning of this organ system instead of the mysterious organs themselves. In 1931, physician Robert Frank first mentioned premenstrual cycle-related changes in medical literature and coined it “premenstrual tension (PMT)”. This phenomenon was defined on the basis of interviews with fifteen women who reported “unrest and irritability, and a desire to find relief by foolish and ill-considered actions” (Taylor, 2006). Until the end of this century, scientific discourse around the subject of premenstrual symptoms consisted solely of misogynistic labeling, with physicians describing the phenomenon as “bitch syndrome” or “witch syndrome”, believed to predominantly affect high-achieving women unsatisfied in their work roles. In the 1950’s Dalton turned it into an official syndrome and popularized the phenomenon. In 1987 Premenstrual syndrome was included in the DSM-IIIR under the name “Late Luteal Phase Dysphoric disorder (LLPDD)” under “unspecified mood disorder”, despite criticism from APA members that it was not a mood disorder and that there was very little evidence for its existence (Taylor, 2006). In the DSM IV its name was changed to “Premenstrual Dysphoric Disorder (PMDD)”.

Hormones were blamed for these phenomena, which means that all of the lingering old ideas about hysteria could now be projected onto female reproductive hormones and the perimenstrual phase of the menstrual cycle. As Grace and MacBride-Steward (2007) revealed trough interviewing women about the etiology of their own pelvic pain, this is indeed exactly what happened. The argument has been made that this debate surrounding the categorization and treatment of premenstrual symptoms goes beyond clashes between feminists, scientists, medical professionals and the APA. Instead, the problem is that pathologizing terms like PMT,LLPPD,PMDD and especially PMS work to attribute symptoms and distress to individual biology. This perspective ignores potential underlying societal causes, facilitating the upholding of the status quo. Instead of having to collectively as well as individually work at challenging internalized patriarchal beliefs about femininity and pathology (Taylor, 2006). This short exploration of the medical history of uterus- and later menstruation associated conditions aligns with this perspective in the collective sense. It shows that for over 2000 years, we have predominantly just adapted beliefs about the cause of women’s health problems to fit the desired solution of getting them married off to procreate.

Unfortunately, women’s capacity to reproduce is still frequently prioritized over their health and wellbeing. This is evident in the prioritization of providing healthcare for conditions that have been proven to directly affect fertility, and the hesitancy of providers to prescribe treatments that might affect fertility. Even if these treatments are more effective and produce less adverse effects compared to alternatives (Osborn et al., 2020; Chan et al., 2023). Furthermore, many individuals seeking help for MCAS/D still have to deal with dismissing and condescending remarks about just having to get pregnant in order to find relief (testimonials retrieved from EndoAwareness NL/BE). This is not only incredibly insensitive given the fact that some of these symptoms may indicate conditions that have a heightened chance of subfertility, it also makes no sense to tell a girl or woman who is not planning on having a child anytime soon to just endure MCAS/D for multiple years or the rest of her life. Comments like this do not only indicate a lack of professionality, they also have no basis in reality. For some conditions like PMDD and endometriosis symptoms may temporarily disappear during pregnancy, but they will likely return postpartum (Osborn et al., 2020). Symptoms may even increase in amount or severity due to the increased responsibility and stress of now having to care for a newborn as well as manage MCAS/D. Additionally, research has shown that perimenstrual symptoms are a significant predictor for postpartum depression, which means they should be addressed before a patient potentially falls pregnant (Castro, Pataky & Ehlert, 2019). Women with children are at a greater risk for developing perimenstrual symptoms and chronic pelvic pain, suggesting that pregnancy, childbirth and our contemporary conceptualization of womanhood and motherhood are more often the cause rather than solution for the problem of MCAS/D (Grace & MacBride-Stewart, 2007; Ussher, 2004; Rosvall & Ekholm, 2016).

10.3 Women just get this

The second myth that needs to be addressed in medical schools is the idea that MCAS/D is just a normal or even inevitable consequence of being born in a body with female reproductive organs. The fact that the majority of people with female bodies do not experience debilitating menstrual symptoms or visit healthcare providers for this specific reason proves that this is simply not true. This pervasive bias is a consequence of the religious belief that labour pain is a punishment for the sins of mankind, and the heavily politicized pathologization of menstruation. This was particularly prominent in the 19th and 20th centuries (Cleghorn, 2021, p. 138-181). Physicians and psychologists developed misogynistic theories about (pre)menstrual problems after studying the most severe cases, and then falsely generalized these theories as if their findings from this particular sample of patients apply to all women. Politicians then used these theories to claim menstruation was a dangerous and debilitating disease in an attempt to keep women from getting the right to vote, and later from entering the workspace. It is telling that the first two women that were allowed to attend medical schools and practice medicine in the 1870’s, Elizabeth Garett Anderson and Mary Putnam Jacobi, were the first medical professionals to actually conduct epidemiologic research into women’s experiences of the menstrual cycle. They found that for the majority of women, menstruation had no debilitating impact on their health or mind. Some of their participants even reported an “increased vigor and nervo-muscular strength” in the week leading up to menses (Cleghorn, 2021, p. 145-150). In spite of these valuable contributions to our understanding of menstruation, the notion that menstruation is a debilitating condition persisted. Over time this excessive pathologization and politicization of the female body have led to the cultural crystallization of the belief that all of these symptoms, no matter the severity or impact, are inherent to female biology. This perspective is fundamentally flawed because it fails to recognize that menstruation is a human bodily function, that can encounter a range of issues with multifactorial etiology, just like any other human bodily function.

10.4 It’s not real

The third myth that needs addressing is the pervasive misconception that women’s own accounts of their symptoms cannot be trusted because they malinger, exaggerate or fake MCAS/D. Propagating the idea that women are to be mistrusted is foundational to constructing and maintaining patriarchal systems. Early Hippocratic authors already argued that women’s accounts about what was happening in their own bodies are unreliable due to their shame and ignorance (Cleghorn, 2021, p. 27-33). However, the medicalization of this specific phenomenon of women lying about medical symptoms has its roots in the emergence and professionalization of the field of neurology in the 17th century. Thomas Willis, considered to be the father of neurology, believed that women’s hysteric symptoms were not a consequence of the evil influences of the uterus. Instead he believed they stemmed from diseases of the nerves and spirits (Cleghorn, 2021, p. 79-85). This split between hysteric symptoms and the uterus meant that men could now also suffer from hysteria, but for them it was given other names like hypochondria (translates to what we now understand as melancholia). In men that presented with these symptoms it was frequently believed to be a consequence of them having lifestyles that were too effeminate. However, because spirits were believed to influence emotions, and women were believed to be at the mercy of their emotions, hysteria was still considered to be a predominantly female disease (Cleghorn, 2021, p. 83). In the 18th century the obsession with women’s emotions and their supposed fragile nervous systems had infiltrated medical discourse and led to the search for the origin of hysteria in the nervous system. Because this search failed, and medical men like Paget and Charcot observed that differentiating hysteria from organic nervous system disorders was challenging, it was concluded that some women must be feigning neurologic disease, and that clinicians could distinguish the two by observing the signs and symptoms carefully (Trimble & Reynolds, 2016).

This was one factor contributing to the popularization of the belief that the realness of women's symptoms needs to be determined by medical professionals. Another significant factor in propagating this idea was the prevalence of colonialist ideology influencing medical theorizing in the 18th and 19th centuries. By that time, women's labour pain was already predominantly perceived as a psychological feeling instead of a physiological fact. Medical men started writing racist and classist medical texts discussing the amount of pain different groups of women were capable of feeling. These texts emphasized that estimations of the realness of women's pain should be made by medical men, based on the feelings, thoughts and mental disturbances of each individual white patient. It was believed that her level of civility determined the level of pain she was capable of feeling. Black women were all perceived as uncivilized and therefore thought of as immune to feeling real pain. This made them ideal subjects for extremely inhumane gynecological experiments contributing to the advancement of the careers of pioneers in the field (Cleghorn, 2021, p. 92-97).

Although few contemporary medical professionals will still adhere to these outright discriminatory and dangerous beliefs, these ideas and practices do form the foundation on which our current systems of gynecological healthcare are built. Their effects are still lingering and remnants of these ideas might to a certain degree be unconsciously present in the minds of medical professionals. For this reason it is crucial that anyone starting a career in healthcare is made aware of common unconscious medical biases they might have, and where these biases come from.

Research has repeatedly proven that prevalent beliefs about women having a high willingness to exaggerate and seek care for MCAS/D are untrue (Henry et al., 2020; As-Sanie et al., 2019; Barrington et al., 2021; Grace & MacBride-Stewart, 2007). This idea contradicts findings about women waiting many years to seek care for these symptoms due to shame, stigma, not knowing what is normal, a lack of trust that healthcare providers will know more, and medical trauma due to previous bad experiences (Henry et al., 2020; Osborn et al., 2020; Chan et al., 2023). The notion that women go to a doctor to fake menstrual or pelvic pain symptoms for amusement or attention is unfounded and likely originates from the excessive sexualization of women's health in the 19th century.

It is not the function of a healthcare provider to decide how real a woman's menstrual cycle associated symptoms are. Even if after comprehensive inquiry an unmet need for being seen or heard is suspected to be a significant factor contributing to the severity of MCAS/D, it becomes the responsibility of healthcare providers to refer such patients to the appropriate resources where this psychosocial factor can be addressed. Assuming symptoms are exaggerated or not real and refusing to provide healthcare is never an appropriate response to individuals presenting with MCAS/D.

11 Practical education

11.1 Gathering and integrating information

The second step to improving menstrual healthcare is providing healthcare professionals with the practical knowledge and skills they need to support individuals in need of care for MCAS/D. The most frequently mentioned provider-related barrier to adequate menstrual healthcare in the reviewed literature was a lack of knowledge on how to diagnose and treat patients. For diagnosing patients students need to learn about the spectrum of symptoms that can be associated with the menstrual cycle, including premenstrual exacerbation of underlying conditions. They also need information about which conditions different symptoms may indicate, what the impact of these symptoms can be on the quality of life, and which medical examinations are appropriate.

Two frequently mentioned barriers relevant for addressing a lack of provider knowledge on how to treat MCAS/D are the lack of integration of different fields of knowledge, and knowledge translation into clinical practice. In order to efficiently treat MCAS/D, there needs to be more research on how to effectively identify and address psychosocial factors impacting MCAS/D. Factors of special interest regarding the treatment and support for MCAS/D are menstrual shame and catastrophic worry. Existing knowledge on the influence of these factors needs to be integrated into the curriculum for students and supplementary trainings for professionals. This is important for creating awareness and an understanding of the potential impact of psychosocial factors on MCAS/D. Additionally, healthcare providers should be made aware of the fact that biomedical treatment modalities like pharmaceutical interventions and surgeries are often not effective and/or desired in treating MCAS/D. Special attention should go to proceeding with caution in prescribing hormonal contraceptives and preserving patients bodily autonomy. Healthcare professionals need to be informed about the adverse effects this medication can have, as well as the fact that it is not a cure for anything potentially menstruation-related. Healthcare providers should be trained in providing patients with the correct information, potential additional and alternative treatment options, and appropriate follow-up attention.

Other information that needs to be integrated into the curriculum are current evidence-based non-pharmaceutical treatment options like massage, psychoeducation, emotion-focused and physical therapies, available TCIM treatment modalities and Chronic pain research. In revising the curriculum it is essential to give special consideration to the language that is used. Existing textbooks must undergo revision to ensure the absence of inaccurate information and unnecessarily gendered language. Terms like “premenstrual syndrome” should be eliminated from medical textbooks and replaced with more descriptive and evidence-based definitions without such a heavily politicized history.

11.2 Time perception, referral and practical tools

A barrier frequently mentioned by healthcare providers as well as patients seeking healthcare is a perceived lack of time for adequate consultation and treatment. To some extend this is a problem that requires policy changes. Guidelines must be updated and providers must have the resources to allocate time to these patients and refer them to the appropriate places. However, providers can always ask their patient to book a second appointment if the first one proved insufficient due to time constraints. In part this perceived shortage of time is due to distorted prioritization, a lack of diagnostic skills and insufficient knowledge about referral pathways. This perspective of time scarcity does not take into account all the time and effort patients now have to spend attempting to educate themselves on medical conditions and treatment options. A lot of time is waisted by patients repeatedly having to convince each new provider of the realness of their menstruation associated symptoms or diagnoses. In the long term, repeatedly refusing MSAS/D patients the care they need can result in them needing even more time-intensive and more expensive treatments compared to when they first sought care. For instance when chronic stress due to hopelessness and being consistently dismissed starts to impact overall health, or when underlying conditions like endometriosis or endometrial cancer spread and become life-threatening or impact fertility, warranting intensive surgeries or IVF treatments.

To save time it is essential that healthcare providers are trained in asking the right questions and using the right tools to efficiently and effectively diagnose the condition and identify factors contributing to symptom severity or distress. Subsequently, they need to know what places to refer these patients to. Examples of evidence-based practical tools that every healthcare provider should be acquainted with are daily symptom tracking tools and questionnaires like the Painful Periods Screening Tool (Hantsloo et al., 2022; Singh et al., 2023). The Painful Periods Screening Tool has been shown to facilitate communication between patient and provider about pelvic pain (Singh et al., 2023). Furthermore, providers need to be made aware of the developing nature of the field of menstrual healthcare, particularly with regards to research on using menstrual blood as a diagnostic tool and research on premenstrual exacerbation, and the development of new evidence-based treatment options. Other tools that could be particularly meaningful are encounter decision aids. These aids are designed for use in clinical settings to inform patients as well as providers about potential treatment options. Encounter decision aids developed for the treatment of heavy menstrual bleeding have been shown to facilitate the shared decision making process (Aarts et al., 2021).

11.3 Menstrual attitudes and conversational skills

Literature on provider related barriers reveals that medical gaslighting of individuals with MCAS/D symptoms is a significant problem. Healthcare providers frequently dismiss and behave disrespectful towards people seeking solutions for MCAS/D. For a large part, this behavior results from negative and dysfunctional attitudes towards menstruation or menstruation associated symptoms (Witzeman & Kopfman, 2014; Eyring, Crandall & Magnusson, 2023). Eyring et al. (2023) found that negative attitudes towards menstruation are intricately linked with cultural expectations individuals have for women and men. Positive attitudes towards menstrual secrecy were associated with gender role expectations and hostile sexism, while endorsing avoidance of activities, denying menstrual symptoms and perceiving menstruation as debilitating was associated with benevolent sexism (Eyring, Crandall & Magnusson, 2023). Hostile sexism is characterized by negative attitudes towards women whose behavior deviates from patriarchal gender roles, and benevolent sexism is characterized by the positive treatment of women that do adhere to these roles. Eyring and colleagues argue that the association between denial of menstrual symptoms and benevolent sexism can be explained by adherence to the belief that women exaggerate symptom severity due to being too weak to handle the symptoms. It was also observed that increased knowledge about menstruation was associated with more positive attitudes towards menstruation (Eyring et al., 2023). These findings suggests that interventions to combat negative attitudes towards menstruation should focus on increasing knowledge about menstruation and addressing hostile as well as benevolent sexist attitudes. Because older generations are more likely to adhere to sexist attitudes, it is particularly important to include these interventions in supplementary training programs for professionals already working in their respective fields (Duncan, Aguilar, Jensen & Magnusson, 2019).

Another factor that may be contributing to the prevalence of medical gaslighting is a lack of professional conversational skills. When healthcare professionals are not trained in communicating with patients about taboo, stigmatized or potentially sensitive topics, this can result in patients feeling dismissed and not taken seriously, even if the provider has good intentions. Durbhakula et al. (2023) found that many anecdotes from people reporting on experiences of medical gaslighting mention providers attributing MCAS/D symptoms to mental health problems, stress, poor nutrition, obesity or a lack of exercise. While all of these factors can contribute to the onset or exacerbation of MCAS/D symptoms or conditions, they are most likely not the sole reason or underlying cause for their presence (Rosvall & Ekholm, 2016). However, educating patients on these contributing factors and decreasing unnecessary worries by normalizing healthy appearance or functioning of bodily systems is an important aspect of providing healthcare. Because giving this kind of advice is generally not normal behavior in human interactions, healthcare providers need to be trained on how to have these conversations.

If for example a young overweight girl that just started high school visits a general practitioner with concerns about moderate cramping and irritability in the days leading up to and during her menstrual period, it is reasonable for a provider to inquire about her understanding of the menstrual cycle, her stress levels and her habits with regards to food and exercise. When the conversation reveals that these factors might be contributing, it may be helpful to explain that mild to moderate cramping is common and not always an indication of a physiological problem. This can help decrease potential worries she might have. It could also be helpful to inform her about the fact that stress management, better nutrition and frequent exercise may have beneficial effects on pain and/or irritability. However, this kind of advice should only be given after ruling out conditions associated with the specific MCAS/D symptoms that are present, and acquiring information about the lifestyle and level of understanding of that specific patient. It should not be an automatic response to everyone with concerns about MCAS/D. Furthermore, the advice should be given in a respectful manner while keeping in mind the sensitivity of these topics (e.g. the excessive value that women are socialized to put on their weight) and with sufficient evidence-based explanation (e.g. explaining how exercise can increase blood flow towards the uterus, potentially relieving cramps). Healthcare providers need to not only be educated and trained in which questions to ask for diagnosing MCAS/D conditions, but also in knowing when and how to ask these questions. Additionally, they should be trained in when and how to provide health-advice on sensitive and stigmatized topics like weight, menstruation, mental health and sexuality. To prevent psychologization or the perception of psychologization of MCAS/D, providers need to be trained in explaining the body-mind connection and the potential impact of psychosocial factors on physiological as well as affective symptoms. Examples of skills that need to be included in these conversational skill trainings are the framing of sensitive questions (e.g. “I will ask you a personal question because …”) and knowing when to ask these questions (e.g. ask about dyspareunia when pelvic pain is mentioned, wait with questions about weight/sexuality until after the patient is fully dressed).

12 Towards a better understanding

12.1 Discussion

The aim of this literature review was to address the unmet needs of people experiencing menstrual cycle associated symptoms and distress, and propose recommendations for educational programs in order to provide healthcare professionals with the right knowledge and tools for supporting these patients. The main research question was "What skills and information do healthcare professionals need in order to provide adequate support to people suffering from Menstrual Cycle Associated Symptoms and/or Distress?". This question was answered with the help of three sub-questions. The first sub-question that was explored is "What are the unmet needs of people experiencing MCAS/D?". Literature was collected and analyzed separately for four different aspects of MCASD due to the gap in existing literature on the overall provider-related barriers to menstrual healthcare. The aspects that were reviewed are endometriosis, premenstrual disorders, pelvic pain and abnormal uterine bleeding.

The review revealed that individuals seeking care for these conditions encounter corresponding neglected healthcare needs. They were not listened to, believed or respected and there was significant diagnostic delay. Depending on the condition on average 7-12 years (endometriosis) to 20 years (PMDD). When MCAS/D was acknowledged patients did not receive adequate information about available treatment options, they were not supported in finding ways of managing symptoms, treatments were not followed up, there was a lack of attention for identifying the cause of MCAS/D and patients were made to feel responsible for their own symptoms. The fact that these neglected healthcare needs are significant in several different healthcare disciplines (first line healthcare, gynecology, endocrinology, psychology, psychiatry etc.) and for various symptoms that are currently associated with menstruation, suggests that the association with the menstrual cycle itself impacts healthcare provider's perception of these symptoms.

The second sub-question that was explored in order to answer the research question is "What are provider related barriers to meeting these needs?". The most frequently mentioned barriers across all reviewed aspects are medical gaslighting and a lack of knowledge on how to diagnose and treat MCAS/D. Upon further examination, this lack of knowledge was not solely due to a scarcity of available information. Instead, several persistent false beliefs and adherence to limiting and dysfunctional ideologies contribute to the maintenance of a lack of prioritization for acquiring the appropriate knowledge. The literature also revealed that the false notion of hormonal contraception or pregnancy being a cure for everything menstruation-related, prevents healthcare providers from actually examining, supporting and treating individuals with MCAS/D. Other barriers include healthcare providers having a tendency to psychologize MCAS/D, and the fact that they frequently hold negative attitudes towards menstruation, menstrual symptoms, chronic pain, TCIM modalities and people with psychological symptoms.

The third sub-question asked what factors underlie and sustain these barriers. The goal of this question was to provide context and better understand where these provider-related barriers come from in order to address them effectively. Trough an historical and psychological analysis of the identified provider-related barriers, several harmful ideologies and false beliefs were identified as factors underlying and maintaining these barriers. The currently dominant biomedical model of care was revealed to possess inherent limitations when applied to MCAS/D, largely due to its foundational principles rooted in positivism and dualism. These ideologies perpetuate hegemonic gender ideals and androcentrism in medicine, and reinforce the tendency to exclusively rely on laboratory results to diagnose conditions or assess treatment efficacy. Moreover, they uphold the segregation and hierarchical valuation of medical and healthcare disciplines.

Three common false beliefs were identified as underlying and maintaining insufficient care and attention for the problem of MCAS/D. The first one is that the health and maturity of a woman is determined by her capacity to procreate, and that pregnancy or menstrual suppression due to an artificially induced simulated state of early pregnancy are cures for anything menstruation related. The second one is that debilitating menstrual symptoms are just a normal aspect of having a female body, and the third myth is that a menstruating individual’s accounts of their own symptoms should not be trusted. The historical analysis revealed that the projection of multiple millennia of medical speculation about hysteria, the six-century long exclusion of women in medicine and the colonialist roots of the professionalization of gynecology functioned as the foundation for shaping these persistent dysfunctional convictions.

All of these findings were utilized to formulate answers to the main research question about what skills and information healthcare providers need, and propose interventions to address this systemic problem. To combat false beliefs and adherence to dysfunctional ideologies it is essential that healthcare providers are informed about the existence of this problem and the key historical factors still influencing contemporary medical practice. Other essential knowledge includes information about the spectrum of menstrual symptoms and conditions, non-pharmaceutical and non-biomedical treatment options, and the impact of psychosocial factors like pain-catastrophizing and menstrual shame on MCAS/D. More attention should go towards knowledge integration and translation into clinical practice and combatting negative attitudes towards menstruation. Practical skills that need to be systematically included in the training modules for professionals are the use of daily symptom tracking tools, questionnaires like the painful period screening tool and encounter decision aids. Additionally, healthcare providers should receive training on how to communicate about stigmatized or sensitive topics, give lifestyle advice and explain the body-mind connection as well as the impact of psychosocial factors.

The argument can be made that the biomedical model of care is not suited to maintain its status as the dominant model of care because it fails to encompass the healthcare requirements for an organ system that draws attention from roughly half the population on a monthly basis, and is fundamentally responsible for our existence on this planet. A narrow focus on this biomedical model in medical schools perpetuates the reduction of menstruation to a purely physiological event and fails to acknowledge millennia of cultural and political tensions projected onto this bodily function. A more functional approach is to implement holistic integrative models that more accurately reflect reality as the standard model of care. Furthermore, it is essential to work towards a better understanding of the function of menstruation on a physiological as well as a psychological and a spiritual level. In doing so, adopting a pathologizing perspective should be avoided. Historically, heightened emotions like sadness, irritability and anger during the perimenstrual phase have been pathologized. However, from an evolutionary psychological perspective it makes sense that a portion of the population experiences an increase in negative emotions in the week leading up to a new phase of potential fertility. Heightened sensitivity to these emotions likely serves an adaptive purpose. For instance, they may increase awareness of potential problems in the environment and motivate the menstruating individual, as well as their social milieu, to address these problems. This mechanism bears potential advantages in preparing for an impending fertile phase as well as for stimulating overall human development.

12.2 Conclusion

This literature review revealed that healthcare needs of individuals experiencing symptoms and distress associated with menstruation are neglected and that healthcare providers are not adequately educated on how to diagnose, support and treat individuals with menstrual health concerns. In order to address this systemic issue medical education needs to include information on the historical context of the origins of this problem, and routinely integrate existing and new relevant knowledge from multiple disciplines into the curriculum. Additionally, healthcare providers need to be adequately trained in conversational skills as well as on how to utilize the appropriate tools for diagnosing and treating these conditions.

12.3 Limitations

A notable limitation of this literature review stems from the expansive scope and interdisciplinary nature of the research questions. As a consequence, the literature was not reviewed systematically. After an initial search, snowball-sampling, content analysis and keyword searches were the main methods for acquiring new information. This means that certain relevant articles may have been overlooked. Additionally, it is important to acknowledge the potential for the presence of subjective bias within this study, as the selection of this topic was inspired by personal negative experiences with healthcare professionals. To mitigate this potential bias conscious steps were taken, including attempts to adopt the perspective of healthcare providers and seeking insight into the underlying causes of this enduring medical oversight.

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